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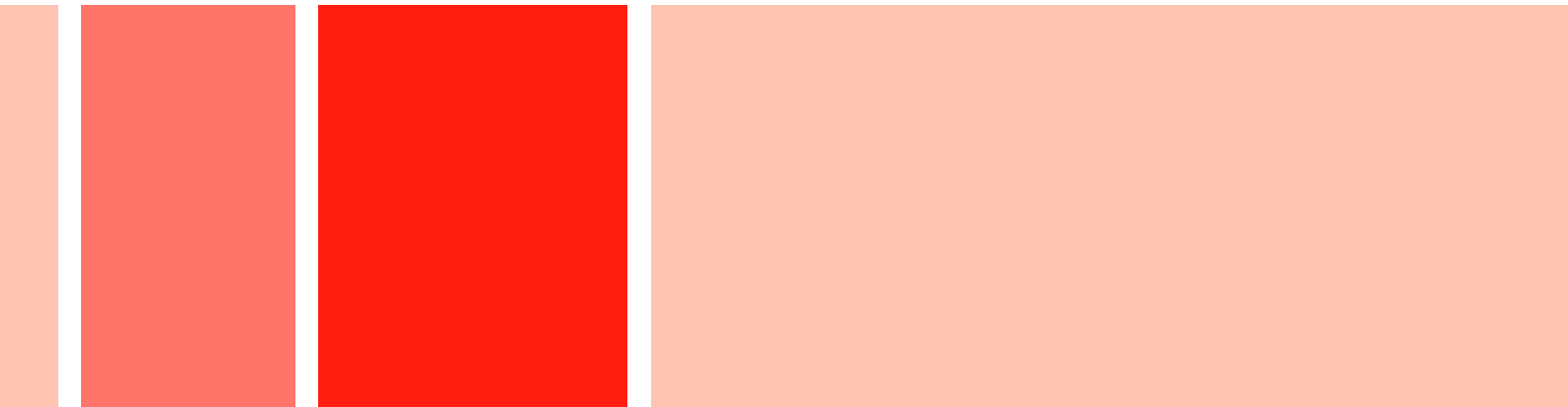
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Religious beliefs and attitudes to organ donation



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Views expressed in this report are those of the researcher and not necessarily those of the Welsh Government.

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Glossary

| | |
|--|---|
| DBD (donation after brain-stem death) | Donation from patients who die as a result of a brain haemorrhage, severe head injury or stroke. A ventilator provides oxygen which keeps the heart beating and blood circulating after death. Organs such as hearts, lungs and livers can be donated by a DBD donor. |
| DCD (donation after circulatory death) | Donation from patients who die in hospital but aren't on a ventilator. Kidneys, and in certain circumstances other organs, can be donated by a DCD donor. |
| Informed or explicit consent system | The individual authorises the removal of their organs after death, for example, by carrying a donor card. |
| Living donation | The donation of an organ from a live patient, usually to a relative related by blood. Kidneys are often donated from living donors as a healthy person can lead a normal life with only one kidney. |
| Opt-in system | An expressed consent system. To be a potential donor, individuals should express their consent i.e. opt in. |
| Opt-out system | A presumed or deemed consent system. Individuals are deemed to have given their consent to organ donation unless they opt out. |
| Organ donation | The process of removal and transplantation of viable organs from donor to recipient. |
| PMP (per million population) | The unit by which donation rates in a country are usually measured. |
| Presumed consent | Legislation that allows the organs to be used for transplantation after death if there is an opportunity to do so, unless the individual has objected during their life. |

Executive summary

- This research set out to explore the relationship between religious beliefs and organ donation, with a particular emphasis on presumed consent.
- The viewpoint of each religion was explored, before reviewing international research investigating the relationship between religion and organ donation across different consent systems. Findings from a small-scale survey of Christians in Wales are also presented, which aimed to address an information gap in engagement work being carried out with faith groups and BME communities across Wales.
- The research sheds light on the complex interplay between religion, culture and ethnicity in forming attitudes to organ donation.

Religion and organ donation

- In theory, all the major religions in Wales (Christianity, Islam, Hinduism, Sikhism, Buddhism and Judaism) support organ donation, although views within Islam and Judaism remain divided, with particular religious tenets about how the dead body should be treated and contention around brain death being the major issues. The latter concern may also be present within particular Buddhist traditions and among some Catholic theologians.

Religion and presumed consent

- Little is known about the views of the major religions on presumed consent, although the limited evidence from faith leaders suggests that views may be unfavourable due to the perception that the legislation undermines individual choice. Furthermore, for Christian faith leaders in particular there is also the belief that the virtue of gift giving intrinsic to the act of organ donation is undermined by this legislation.

Christianity and organ donation

- There is little in the way of conclusive evidence regarding the role of Christianity in organ donation. The predominantly Christian countries of Europe and the United States tend to have well-established transplantation systems, higher rates of donation and populations with positive attitudes towards donation. Evidence suggests that the Christian faith may not play much of a role in willingness to donate, with it being viewed as more of an individual matter.
- In terms of what is known about the role of the Christian faith, research suggests that it may be strength of religious belief (or perhaps conservativeness of belief) rather than religious teachings that act as barriers to donation.

- Research has also suggested that interpretation of one's relationship with God is more likely to be cited as a barrier to donation than interpretation of religious teachings.
- Beliefs about the need for bodily integrity, or organ donation interfering with traditional funeral arrangements, were also found to be significant barriers to donation.
- These barriers may be more significant among Black Africans and Black Caribbeans than among Whites (in UK and United States), with bodily integrity being a particularly significant barrier, transcending religious beliefs.
- The influence of subjective norms (the perceived beliefs of those closest to you) on BME groups also means that religious beliefs may have an indirect influence on donation decisions. For example, perceiving parents to oppose donation, possibly on religious or cultural grounds, acts as a barrier for an individual who in theory has a positive attitude towards donation.

Christianity and presumed consent

- Limited research among UK Christian faith representatives suggests attitudes to presumed consent may be unfavourable due to the legislation being perceived to undermine the 'gift of life' virtue and individual choice.
- A small-scale survey of Christians in Wales, conducted as part of this research, found the majority of respondents in favour of presumed consent, believing that it will not undermine either individual choice or the gift of life virtue. However, those against the legislative change were opposed to it on grounds that they perceive the legislation as undermining individual choice, giving the government too much control.
- Those who already experience multiple barriers to donation in general may be less likely to have favourable attitudes to such legislation.

Islam and organ donation

- Whilst the majority of Muslim countries have sanctioned both living and deceased organ donation, opinion remains divided among scholars, largely due to differences in opinion about the definition of death.
- Research suggests that questions of religious permissibility act as a major barrier to donation among Muslims in both Muslim and non-Muslim countries, despite fatwas approving organ donation.
- Perceived impermissibility was more commonly expressed in research among South Asians. This may be due to the majority of Muslims in the UK being of Indo-Pakistani descent where scholars tend to hold more conservative attitudes towards donation.

- Research in the UK found little knowledge of existing fatwas sanctioning donation, suggesting that their influence may be limited.
- Religious texts and the advice from the local mosque were found to be the most influential in decisions about donation; followed by the influence of family.
- Perceived religious impermissibility was grounded in interpretations of religious texts and centred on the need for bodily integrity and for the burial to be carried out as quickly as possible.
- Barriers may be difficult to shift due to the influence of religious texts in guiding decisions about organ donation.
- The limited research among faith leaders found similar views to the wider population. Faith representatives have argued that more needs to be done to ensure knowledge of organ donation permissibility filters down to the grassroots level.

Islam and presumed consent

- Little is known on this, but research in the UK found faith representatives to be supportive of organ donation but opposed to presumed consent on ethical grounds, due to the perception it undermines individual choice.
- Muslims in Singapore have been included in the Human Organ Transplant Act (HOTA) since 2008, following campaigns to be included in its presumed consent legislation. Prior to this, Singapore's priority system put Malay Muslims at a significant disadvantage due to non-pledgers being accorded a lower priority on the donor waiting list. However, improvement in donation rates from this group since their inclusion has so far been small. No research was found exploring public attitudes to organ donation and presumed consent in Singapore.

Hinduism, Sikhism and organ donation

- There is nothing within Hinduism or Sikhism prohibiting organ donation.
- Barriers to donation in India – which has large Hindu and Sikh populations – have been attributed to wider factors, including a lack of knowledge about donation and brain death, poor transplantation and public healthcare infrastructure and cultural acceptance of the illegal organ trade, making living donation the norm.
- Research found barriers to donation were likely to be related to bodily integrity and family refusal rather than issues of religious permissibility, suggesting that concerns around donation are more cultural rather than religious in nature.

- Research among Hindus and Sikhs in the UK supports this, with bodily integrity and family refusal being more likely to be cited as barriers than religious impermissibility. However, questions regarding religious permissibility were still raised, albeit slightly more so among Hindus.
- The consent of the family was identified as important for both Hindus and Sikhs, but was found to be particularly significant for Hindus, with deference to elders being commonly cited as a reason for unwillingness to donate.

Hinduism, Sikhism and presumed consent

- The little research available among UK Hindu faith representatives suggests this consent system is not preferred due to the belief that it undermines individual choice.

Buddhism and organ donation

- There is nothing within Buddhism prohibiting organ donation, although issues concerning the definition of death may be apparent within some traditions.
- The predominantly Buddhist countries of south-east Asia have low donation rates, with limited transplantation infrastructure and public healthcare in general. However, huge cultural barriers to donation also exist due to a lack of acceptance of brain death, which is still not legally recognised in China, and was found to be a major barrier to donation in research conducted in Japan.
- Cultural views associated with Confucianism such as the need for bodily integrity due to filial piety (the virtue of respect for one's parents and ancestors), was a common barrier to willingness to donate in research conducted in China, despite there being positive attitudes towards donation.
- These beliefs were also found to be barriers in research conducted among individuals of Chinese descent living elsewhere.

Buddhism and presumed consent

- The little research available among UK Buddhist faith representatives suggests this consent system is not preferred due to the belief that it undermines individual choice.

Judaism and organ donation

- Views on organ donation remain divided within Judaism, with some opposing donation due to beliefs about how the dead body should be treated, and differing definitions of death. Low organ donation rates in Israel have been attributed to the lack of acceptance of brain death.

- Research shows that the belief that organ donation is prohibited under Judaism due to the Halachic definition of death acts as a significant barrier to donation.
- Contention around brain death was also found to negatively impact on donation rates due to reluctance among medical staff in Israel to discuss donor related topics with families, particularly brain death, thereby limiting donation opportunities.
- Research conducted elsewhere also found perceived religious prohibition and beliefs about the need for bodily integrity being cited as the reasons behind unwillingness to donate.

Judaism and presumed consent

- Recent ministerial debates in Israel considering potential legislation to introduce presumed consent resulted in the Bill being rejected.
- The little research available among UK Jewish faith representatives suggests this consent system is not preferred due to the belief that it undermines individual choice.

Other barriers to organ donation

- Given that organ donation rates among Black and Minority Ethnic (BME) groups tend to be lower than for the general population, the review also identified a number of other barriers found to be significant among BME groups in the UK regardless of religious belief, including:
 - Lack of understanding and fear about the transplantation process in general.
 - Sensitivity or taboo surrounding the matter.
 - Medical mistrust.
- It is important that these barriers are addressed if communication strategies aim to tackle the current disadvantage BME groups experience in relation to organ donation, with BME groups being both more likely to need an organ transplant and less likely to be represented on the organ donor register.

Recommendations for engaging with different faith groups

- In light of the findings, this review has helped to identify a number of messages and methods for engaging with different faith groups, for example:

- Providing information about the transplantation process to allay misconceptions with regard to bodily mutilation and interference with traditional burial processes.
- Engagement with faith leaders and grassroots networks among faith and BME groups where their influence is important, or where there are high levels of medical mistrust. For example, the role of faith leaders could be used in Muslim communities to raise awareness regarding Islam's stance on organ donation.
- Engagement with faith leaders is also important where they too have low knowledge of the organ donation process.
- A peer-led approach may be effective in communities where family relations are a particularly important source for gaining culturally sensitive health information.

Current evidence gaps

- Finally, this review has identified evidence gaps where further research could add value to communication and engagement strategies. These include:
 - The degree to which religious leaders' views about organ donation and presumed consent influences or reflects that of lay followers. The survey of Christians living in Wales included in this report provides a small insight into this but more research may be useful.
 - More research with Muslims of different ethnicities would be helpful in order to disentangle cultural and religious beliefs.
 - Of the major religions, understanding attitudes to presumed consent among Buddhists, Hindus and Sikhs is particularly lacking.

1. Introduction

From December 2015, the Human Transplantation (Wales) Act will come into full effect changing the system of consent for deceased organ donation in Wales from opt-in to opt-out (also known as ‘deemed’ or ‘presumed consent’). This means that an individual who has not opted out in their lifetime will be considered to have given their consent to organ donation. Clinical teams will be encouraged to treat surviving relatives sensitively and will not insist on donation in cases of distress. It is hoped that such a change will create a positive culture around organ donation resulting in it being seen as a norm rather than an exception, narrowing the gap between those who say they would become a donor and those who actually do (Welsh Government, 2012a).

To prepare members of the public for the new legislation, the Welsh Government is currently implementing a communications campaign to ensure that the public is informed about changes and the choices they can make. Findings from public attitudes surveys suggest that the majority of the public in Wales are in favour of organ donation and supportive of the changes to the legislation (Welsh Government, 2014).

However, the role of the family is also considered an important factor that impacts on donor rates. Family refusal rates for the UK in 2012 stood at 43 per cent (Council of Europe, 2013). This high refusal rate has been partly attributed to family members not knowing the wishes of the deceased, as evidence suggests that family members make decisions in line with the wishes of the deceased in 90 per cent of cases when the wishes are known (Siminoff et al, 2001; NHSBT, 2013b). Therefore, discussing donation wishes with the family is key for increasing donation rates and is reflected in the Welsh Government strategy (2012b) to use campaigns to encourage individuals to discuss their wishes.

As recent survey data suggest that the majority of adults living in Wales have not discussed their wishes with family members (Welsh Government, 2014), the potential success of the new legislation may in part rest upon the impact of the campaigns leading up to its enforcement. Although the family will have no legal veto over the expressed or deemed wishes of the individual, in practice donation is unlikely to go ahead in cases where the family is in distress, making the discussion of wishes an important factor in raising donation rates (Welsh Government, 2012a).

Evidence also suggests that refusal rates are linked to religious beliefs and ethnicity (Welsh Government, 2012a). Recent data from the NHSBT Potential Donor Audit 2012/13 support this. Consent rates are significantly higher when the donor is White, at 61 per cent as opposed to 33 per cent for BME groups. A significant difference remains even after age and sex are accounted for. The most common reasons for family refusal to consent to donation are provided in Table 1.1, below.

Table 1.1: NHSBT Potential Donor Audit Summary Report April 2012-March 2013

| Reasons given why family did not give consent | DBD ^(a) | | DCD ^(b) | |
|--|--------------------|----|--------------------|----|
| | N | % | N | % |
| Patient had stated in the past they did not want to be a donor | 75 | 21 | 155 | 18 |
| Family were not sure the patient would have agreed to donation | 46 | 13 | 140 | 16 |
| Family did not want surgery to the body | 42 | 12 | 49 | 6 |
| Family felt it was against their religious/cultural beliefs | 30 | 8 | 26 | 3 |
| Strong refusal – probing not appropriate | 30 | 8 | 63 | 7 |
| Family felt the patient had suffered enough | 23 | 7 | 67 | 8 |
| Family were divided over the decision | 20 | 6 | 52 | 6 |
| Family did not believe in donation | 16 | 5 | 35 | 4 |
| Family felt the body needs to be buried whole (unrelated to religious or cultural reasons) | 15 | 4 | 29 | 3 |
| Family felt the length of time for the donation process was too long | 11 | 3 | 128 | 15 |

(a) DBD = donation after brain-stem death

(b) DCD = donation after circulatory death

While this illustrates that uncertainty of the deceased's wishes is a limiting factor, the most common reason for refusal was knowledge that the family member did not want to be a donor. The third, fourth and fifth most common reasons given for family refusal were: not wanting surgery to the body, the family feeling organ donation was against religious/cultural beliefs and strong refusal (NHSBT, 2013^b). Therefore attitudes towards donation of either the deceased (when known) or family members may still represent a challenge to increasing donation when the new legislation comes into force.

Raising donation rates from BME groups perhaps represents one of the biggest challenges for the new legislation. There is a greater need for organs among BME groups, with Asian and African-Caribbean individuals being three times more likely than the White population to need a transplant due to higher prevalence of type II diabetes, which accounts for 27 per cent of those on the UK waiting list (Randhawa, 2012, NHSBT, 2013^c); and under-representation on the donor register.

This disadvantage is further compounded by higher rates of family refusal. Recent data for Wales show one out of the 52 deceased donors was from a BME group, resulting in a shortage of suitable organs (NHSBT, 2013^d). In terms of understanding why this may be, evidence suggests that knowledge about donation and values about life and death are likely to influence decisions on organ donation. However, little is known about the influence of faith and belief in such decisions (Randhawa, 2011, 2012). If future legislation is successful it should bring about improved outcomes for disadvantaged BME groups, however this is likely to be dependent on the success of the Welsh Government's communication and engagement strategies with BME and faith groups (Welsh Government, 2012^a).

Opposition to the legislation has been voiced by a number of faith leaders in Wales. For example, the Catholic Bishops in Wales and the Bench of Bishops of the Church of Wales opposed the legislation due to the belief that presumed consent undermines the gift of giving life they feel is intrinsic to the act of donation. There was also unease regarding the assumption that failure to opt-out equated to consent. These concerns were also echoed by the Muslim Council of Wales and the South Wales Jewish Representative Council. Given that the aim of the opt out legislation is to create a positive culture around organ donation, any barriers to organ donation, including those presented by religion and faith, need to be adequately explored and addressed through the provision of correct information to ensure everyone in Wales knows the options available to them under the new legislation (National Assembly for Wales, 2013).

The following chapters aim to explore the relationship between faith, religion¹ and organ donation. The viewpoint of each religion will be discussed, before considering international research that has explored the relationship between religion and organ donation across different consent systems. The volume of evidence identified for the different religions varies (with larger evidence bases for Christianity and Islam), and this is reflected in the length of the chapters. In addition, given the relatively limited evidence base for Hinduism and Sikhism, and the close relation of their core values and beliefs, the evidence concerning these two religions is considered within the same chapter.

In addition to reviewing existing research, findings from a small-scale survey of Christians in Wales are also presented. This survey aimed to address an information gap in engagement work being carried out for the Welsh Government with faith groups and BME communities across Wales to promote discussion of organ donation, and facilitate understanding of the new law. While this engagement work is helping to aid understanding of attitudes towards organ donation and the new law among different faith groups in Wales, little is currently known about the views of Christians.

The final chapter of this report summarises the key insights of the research, identifying messages and methods for engaging with different faith groups, and highlighting evidence gaps where further research could add value to communication and engagement strategies.

¹ The terms 'religion' and 'faith' are used interchangeably in this report due to their close association. A religion is an organised system of doctrines and beliefs, whereas faith represents the strength of belief in the particular religious views or doctrines.

2. Overview of religion and organ donation

In principle, all the major faith groups in the UK support organ donation (Randhawa et al, 2010^a). However, research has suggested that questions of religious permissibility act as a barrier to donation (Randhawa, 1998), with religion commonly cited as a reason for refusal to donate the organs of a deceased family member (NHSBT, 2013^b). The views of the major faith groups therefore need to be explored in more detail to determine any ambiguity which may play a role in influencing attitudes to organ donation.

Table 2.1 (below) shows the breakdown of the 2011 census data regarding religious affiliation in Wales. Given the potential for a wide variation of beliefs that could be incorporated under the 'other religion' category, this review will focus on Christianity, Islam, Hinduism, Buddhism, Sikhism, and Judaism.

Table 2.1: Religion residents in Wales (2011)

| Religion | Number (thousands) | Per cent |
|----------------------------|--------------------|----------|
| Christian | 1, 763 | 57.6 |
| No religion | 983 | 32.1 |
| Muslim | 46 | 1.5 |
| Other religion | 13 | 0.4 |
| Hindu | 10 | 0.3 |
| Buddhist | 9 | 0.3 |
| Sikh | 3 | 0.1 |
| Jewish | 2 | 0.1 |
| <i>Religion not stated</i> | 234 | 7.6 |

Source: ONS 2011 Census: Key Statistics for Wales (March 2011).

2.1 Christianity

All Christian denominations view organ donation as an act of love and an expression of solidarity (Oliver et al, 2010; NHSBT, 2012^a). Public endorsement of organ donation has been expressed by both Pope Benedict XVI, who declared that he carried an organ donor card on him at all times, and Pope John Paul II who praised organ donation as an act of Christian love in the *Evangelium Vitae* (Oliver et al, 2010).

In theory, all denominations of Christianity accept the notion of brain death (NHSBT, 2012^a). This position was made explicit in 2000 by Pope John Paul II in an address he gave to the international conference of Organ Transplant Specialists, where he formally acknowledged the criteria of brain death in determining death (Pope John Paul II, 2000). However, brain death is still debated among Catholic theologians and bio-ethicists, and its rejection by some is used to oppose deceased donation (Bresnahan and Mahler, 2010).

2.1.1 Christianity and presumed consent

In 2007, a response to the EU Commission's Communication on Organ Donation and Transplantation policy by the Church of England declared organ donation as a Christian duty, yet it remained inconclusive about the potential introduction of an opt-out system. Those favouring an opt-in policy would tend to stress the importance of the Christian celebration of the voluntary gift aspect of donation, whereas those favouring the opt-out would stress the Christian emphasis on solidarity and making sacrifices for others. However, concerns were raised about the broader moral implication such a shift may entail in terms of the relation between the individual and the state. It recommended that this concern be taken into account and carefully weighed against the moral need for more organs when considering such a change (Butler, 2007).

However, the Church of England's response to the NHSBT (2013^c) Organ Donation strategy was clear on the issue arguing that the current opt-in system best reflected the balance between the individual, the family and the state, with the presumption that the state does not have right to tell individuals and their families how their body can be used. Although they recognised that under such legislation individuals can choose to opt-out, it was felt this represented an unnecessary intrusion by the state into the rights of the individual (Church of England, 2012).

These concerns were mirrored in opposition to the Welsh legislation by the Roman Catholic Church in Wales, the Church in Wales, and the Wales Orthodox Mission in a joint response letter to the Welsh Government White Paper. Such concerns are ethical rather than theological, and centre on the belief that opt-out legislation undermines Christian virtue of giving a gift of life intrinsic to the ethos of organ donation (Stack et al, 2013). With regard to the Catholic Church, this ethical viewpoint has been informed by the position of Pope John Paul II, who stated that transplantation "presupposes a prior, explicit, conscious decision on the part of the donor or of someone who legitimately represents the donor, generally the closest relatives" (Pope John Paul II, 1991).

Overall, the Christian view towards organ donation is positive, yet ethical concerns exist about presumed consent undermining the gift virtue believed to be intrinsic to organ donation.

2.2 Islam

Views on organ donation within Islam remain divided. One school of thought emphasises the sanctity of human life, and uses the principle that necessity makes what is usually prohibited permissible (*al-dururat tubih al-mahazurat*), to support organ donation to save the life of another. The other school of thought argues that organ donation cannot be permissible in Islam, because it compromises the special honour accorded to man by violating the sanctity of the human body (Sharif, 2012; NHSBT, 2012^b). Other issues include a lack of acceptance of brain death by some in the religion, and arguments that organ

donation undermines the authority of Allah, due to the body belonging to Allah (Sharif, 2012).

The majority of jurists support organ donation. This is evident in the majority of fatwas (rulings on a matter of Islamic law) sanctioning organ donation in the Muslim world (Sharif, 2012). The Muslim Law Council UK issued its own fatwa in 1995 permitting organ donation following a consultation with a group of scholars, making references to classical Islamic texts to support their position.

Another school of thought that opposes organ donation is reflective of the majority of Indo-Pakistani scholars, who have issued fatwas opposing donation (Ghaly, 2012). For example, the Islamic Fiqh Academy of India only accept donation from living donors (NHSBT, 2012^b). This fatwa also stipulated that if someone did express a wish to donate their organs after death, this wish could not be considered a valid testament (Ebrahim and Mohsin, 1998; cited in Ghaly, 2012).

Despite the numerous rulings supporting organ donation, there is still uncertainty regarding its permissibility within Islam, with contention surrounding brain death (Sharif, 2012). Although Islamic scholars have recognised the clinical role of brain death (El-Shahat, 1999), it is not considered death from the perspective of Islamic metaphysics where a person is not considered dead until rigor mortis sets in. This set of beliefs is grounded in Islamic theology and therefore it may be difficult to assure families that a family member with brain-stem death is truly dead in order to allow donation to happen (Abdulazziz et al, 2007 cited in Bresnahan and Mahler, 2010).

Views on brain death may have some influence over the fact that most transplants in Muslim countries are still from live donations (Shaheen, 2009). For example, in 2006, 13 per cent of kidney donations in Iran were from deceased donors, and around a quarter in Turkey, Saudi Arabia and Kuwait (Einollahi, 2008 cited in Oliver et al, 2011), whereas the recent figures for the UK show that 62 per cent of kidney donations were from deceased donors (NHSBT, 2013^a). Despite legislation sanctioning both living and deceased organ donation in many Islamic countries, brain-stem death is still not legally recognised in some countries, such as Egypt and Morocco (Shaheen, 2009). It is difficult, however, to conclude how far differences in deceased donation can be attributed to religion given the logistical issues that are also at play in many Muslim countries (Shaheen, 2009; Oliver et al, 2011). Given the divergence in thought, Muslims in Britain are encouraged to consult their local imam on the matter (NHSBT, 2012^b).

2.2.1 Islam and presumed consent

Singapore, which has presumed consent legislation in place, has a diverse religious population with people of Muslim faith representing around 13 per cent of the population (Kwek et al, 2009). Muslims were initially exempt from the presumed consent legislation but in 2007 a fatwa was passed allowing Muslims to be included in the law, making it the first country to have a fatwa

approving Muslims to be included in a presumed consent system (Zainal, 2012; MUIS, 2013). The Human Organ Transplant Act (HOTA) was subsequently amended in 2007 to take account of this (Kwek et al, 2009).

The European Council for Fatwa and Research (ECFR) issued a fatwa in 2000 stating that in countries where presumed consent legislation is in place the “absence of one’s refusal to be an eventual donor in clear terms would be tantamount to an implied consent” (Majlis, 2002:180-181; cited in Ghaly, 2012). However, little is known about the impact of this particular fatwa on Muslims in Europe or of the influence of fatwas in general (Ghaly, 2012).

Fatwas issued in the Middle East emphasise donation as a matter of individual choice, therefore informed consent from either the deceased individual or their family is a pre-condition for donation (El-Shahat, 1999). This is underpinned by the belief in the intellectual autonomy of the individual in Islamic law, with free will, rationality and personal accountability being central to Islam’s view of man (Kamal, 2008). Indeed, this principle mirrors concerns that were raised by the Institute of Islamic Jurisprudence and the Islamic Medical Association in response to the consultation on the Human Transplantation (Wales) Bill, with both bodies arguing that opt-out legislation undermines individual choice (Butt, 2013; Katme, 2013).

Overall, views towards organ donation and presumed consent are divided within Islam. Whilst the majority of Muslim countries have sanctioned both living and deceased organ donation (El-Shahat, 1999), organ donation is still a matter of contention due to divergence of opinion among Islamic scholars (Sharif, 2012).

2.3 Hinduism

No religious law within Hinduism prohibits organ donation. Indeed, there are many references within the Hindu scriptures which could be interpreted to support organ donation, with virtue of giving one’s organs to help save someone else’s life sitting well within the faith’s emphasis on selfless giving (daan) (Oliver et al, 2010; NHSBT, 2012^c). The Hindu belief in reincarnation (and the use of body parts to benefit others) is also thought to provide a favourable opinion towards organ donation, with little emphasis being placed on the integrity of the dead body being crucial for the reincarnation of the soul (NHSBT, 2012^c).

Organ donation has been promoted by the former President of the Hindu Council UK, Dr Bal Makund Bhala, who publicly declared that he is on the organ donor register and encourages other Hindus to do the same (NHSBT, 2012^c).

In India, where Hindus make up the majority of the population, organ donation legislation was only passed in 1994 in an effort to curb the organ trade (Jha, 2004; Shroff, 2009). Despite this law, low rates of deceased donation remain. This has been attributed to a number of factors including a lack of knowledge

about organ donation and the brain-stem death criteria, and limited public healthcare provision and organ donation infrastructure (Veerappan, 2012).

Given there is no single spiritual leader within the Hindu faith, it is likely that views on organ donation will differ among religious leaders. Therefore cultural and personal influences may be more at play in forming attitudes towards organ donation among Hindus. With regard to presumed consent, there has been no documented response to the new law in Wales from Hindu faith representatives.

2.4 Buddhism

There is nothing explicit within Buddhism to suggest whether it is in favour of or against organ donation. Representatives of Buddhist organisations in the UK have tended to stress that the Buddhist virtue of alleviating the suffering of others would mean that organ donation would be viewed favourably (NHSBT, 2012^d).

In terms of the process of donation, maintaining integrity of the body is not seen as crucial within Buddhism but the dying process is considered an important time, and should be treated with care and respect (Oliver et al, 2010).

Although Buddhism promotes all acts that may help to alleviate the suffering of others, there is variation within different Buddhist traditions regarding the acceptability of organ donation (NHSBT, 2012^d). For example, within Tibetan Buddhism, it is believed that the spirit may remain in the body several days after breathing has stopped and should not be disturbed to avoid negatively impacting on the individuals' rebirth (Oliver et al, 2010). In terms of defining death, ancient Buddhist scriptures define death as when the spirit leaves the body and this is determined by the loss of vitality (ayu), heat (usma) and sentiency (vinnana). This definition, therefore, may not sit well with the concept of brain-stem death (Keown, 2005).

With regard to presumed consent, no documented concerns have been raised to the new Welsh law by Buddhist faith representatives.

2.5 Sikhism

The Sikh emphasis on putting the needs of others before oneself, selflessness (seva), could arguably include the donation of one's organ. The Sikh belief in rebirth also means that the body is viewed as a vessel, suggesting that there is no religious requirement for the body to remain intact after death. Sikhism therefore looks upon organ donation favourably. Lord Singh, director of the Network of Sikh organisations in the UK, declared that he and everyone in his family carries a donor card and has encouraged all Sikhs to do the same (NHSBT, 2012^e).

As with Hinduism and Buddhism, no documented concerns have been raised with regard to the new law in Wales by Sikh faith representatives.

2.6 Judaism

Although in principle Judaism sanctions and supports organ donation, decisions regarding organ donation can be difficult with some Orthodox Jews opposing organ donation due to the definition of death in Jewish law. Furthermore, similarly to Islam, the Jewish principles of saving a life (pikauch nefesh) and the honour and respect that is due to the dead (kavod hamed), come into conflict with one another when it comes to the matter of organ donation, making it difficult for families who are faced with this decision (NHSBT, 2012^f).

Those opposing organ donation do so on the grounds of adhering to the principle of honouring and respecting the dead (kavod hamed). This means that the body should not be interfered with, and buried within 24 hours after death. However, Rabbis in favour of organ donation argue that the principle of saving a life (pkauch nefesh) overrides this and should be used to promote the act of donation (Halachic Organ Donor society (HOD), 2011; Sacks, 2011).

Although brain death is recognised by many leading Rabbis, including the Chief Rabbinate of Israel, some Jewish (Halachic) Law does not recognise it as death. This is because Halachic law defines death as the cessation of cardio-respiratory activity. Following this Talmudic definition would mean that transplantation in this instance would be tantamount to murder (Jokowitz, 2008; Bresnahan and Mahler, 2010; Sacks, 2011).

The contention around brain death has meant that donation is so problematic for some Orthodox Rabbis that they have gone as far as to prohibit the carrying of donor cards as they are currently printed in Britain (Taylor, 2011), while in Israel, the ultra-Orthodox community issued their own anti-donation card (Haaretz, 2008). In response to this issue, the Halachic Organ Donor society in the United States issues donor cards which allow individuals to choose the circumstances of death under which they would be willing to donate their organs (Taylor, 2011).

Given the differences of opinion on this issue, organ donation in Judaism tends to be considered case by case with a rabbinic authority before a decision about donation is made (NHSBT, 2012^f).

2.6.1 Judaism and presumed consent

Concerns about the new law in Wales have been raised by the South Wales Jewish Representative Council. These included presumed consent not being considered an adequate definition of consent, a lack of detail regarding the definition of death in the Act (which may be problematic with some Jews who do not recognise brain death), and issues concerning the role of the family in the donation process. The latter is particularly important within the Jewish community given the emphasis that is placed on the role of the family in Jewish practices surrounding organ donation. Ideally, the family should

consult religious authorities and be given time to reflect before coming to a decision about donation. Although they recognise that the family will still have an important role in the new legislation, there is still concern that this may be undermined in light of deemed consent (Soffa, 2013).

2.7 Summary

All interpretations of the major religions in Wales include support for organ donation. However, there are concerns regarding brain death and conflicts around particular death rituals within Islam and Judaism. The concern around brain death may also be present within particular Buddhist traditions and among some Catholic theologians. With regard to presumed consent, research among faith leaders suggests that the major denominations on the whole oppose presumed consent, mainly due to concerns relating to individual choice and autonomy. The same concerns have been raised in response to the legislation in Wales by Muslim, Jewish and Christian representatives.

The following chapters aim to explore the degree to which these beliefs are mirrored by faith leaders responsible for communicating and disseminating the views of their faith at a community level, and those following the faith. This will be done by identifying research that has been conducted internationally across different consent systems, and exploring the influence of religion on organ donation.

3. Research exploring the role of Christianity in organ donation

This chapter brings together existing research investigating the relationship between Christianity, organ donation and presumed consent. In addition, the findings from the small-scale survey of Christians in Wales are presented and discussed.

3.1 Catholicism and organ donation

Roman Catholicism is the largest Christian denomination in Europe. Almost half of the EU population (48 per cent) consider themselves Catholic (European Commission, 2012). This is followed by Protestantism (12 per cent), Orthodox (eight per cent), and other Christian denominations (four per cent).

Research suggests that countries with a higher proportion of Catholics have higher rates of organ donation than countries with a smaller Catholic presence (Gimbel et al, 2003). This would appear to be consistent with the positive view of organ donation espoused by the Pope. However, making a causal link between faith and donation is difficult, with Catholicism being one of many factors that predict willingness to donate. For example, presumed consent legislation is also correlated with higher rates of donation (Gimbel et al, 2003). Furthermore, many of the countries that currently have presumed consent legislation are also predominantly Catholic (Cameron and Forsythe, 2001; Neto et al, 2007). This could lead to the suggestion that, contrary to the views regarding consent expressed by the Catholic Church, Catholics may not find presumed consent problematic.

However, it has also been suggested that high donation rates and presumed consent systems found in some Catholic countries may have more to do with the legal system rather than the influence of religion. The predominantly Catholic countries of southern Europe have a legal system grounded in Roman law; whereas the predominantly Protestant countries of northern Europe have one based on common law. The former places an emphasis on the individual duties to the state and the latter on individual rights and determination. The type of legal system has also been shown to be a statistically significant factor in influencing donation rates (Neto et al, 2007) and may explain why presumed consent legislation is more prevalent in southern Europe (Cameron and Forsythe, 2001). Given the multitude of factors that can influence donation rates, it is difficult to tell to what degree the positive endorsement for organ donation by the Catholic Church helps to form positive attitudes to organ donation.

Research attempting to specifically explore the influence of the Christian faith on willingness to donate organs in Europe is sparse. However, one such study of nuns, priests and theology students conducted in Poland (Wejda et al, 2012) – a largely Catholic country with a presumed consent system in place – found that the vast majority of participants accepted organ donation, and were willing to become donors after death. However, most were not

aware of the current legislation in Poland, or of documents issued by the Catholic Church with regard to organ donation, with information tending to be obtained from the media. Therefore, although this research supports the positive attitude of the Catholic Church to organ donation, it is perhaps surprising that the majority of participants obtained their knowledge and information regarding donation from media sources rather than the teachings of the Catholic Church (Wejda, et al, 2012). This reflects how difficult it is to assess how Catholicism has shaped attitudes towards donation. However, this finding is pertinent given the high religiosity among the participants, as level of religiosity has been identified as a factor associated with a negative perception of organ donation in other studies (Lopez et al, 2006; Rumsey et al, 2003).

3.2 Religiosity and willingness to donate

Spain has presumed consent legislation and the highest rate of organ donation in the world (35.1 deceased donors PMP²) (Council of Europe, 2013). Data on family refusal also shows this decreased from 46.3 per cent in 1990 to 12.5 per cent in 2004, with refusal rates tending to be higher among immigrants than the rest of the population (Frutos et al, 2005). Further research carried out by Lopez et al (2012) found that Muslim, Buddhist and Jewish respondents tended to have less favourable attitudes towards donation. Furthermore, among Catholic respondents, disposition to donate was highly related to religiosity, with those who identified as being more religious being less likely to support donation.

In the United States – where donation rates are relatively high (25.8 PMP, Council of Europe, 2013), the need for organs still outstrips organs donated. Religious views have been identified as a factor influencing willingness to donate, with religion tending to be cited as a barrier to donation. A small scale study by Rumsey et al (2003)³ investigated the influence of knowledge and religiousness on attitudes to organ donation among Christians. Their research found that the strongest reason for opposing organ donation was belief that Christianity opposes donation. Those who rated themselves as highly religious, were less likely to be accepting of organ donation (Rumsey et al, 2003), consistent with the research conducted in the European context by Lopez et al (2012).

Morgan et al's (2008)⁴ qualitative study explored the reasons individuals cited for carrying or not carrying donor cards. The research found that the majority of those who expressed a positive attitude to organ donation did so on the basis of the belief that donation was something which was positively

² Organ donation rates per million population.

³ The Organ Donation Attitude Survey (ODAS) was conducted among 190 undergraduate students (114 women and 76 men).

⁴ Interviews were conducted with 78 American family pair dyads in order to reveal the reasoning behind particular attitudes by getting the pairs to answer and discuss questions about the respondents' views on organ donation. The research aimed to explore family communication on the issue and did not explicitly seek to uncover the role of religion in influencing decisions.

encouraged by the Christian faith. It also contrasted with Rumsey et al's (2003) research, as strength of belief was also associated positively with organ donation. The study suggests that it may actually be the conservativeness of religious belief, rather than religiosity itself, that may be the underlying factor in forming attitudes to donation. Research exploring the relationship between conservativeness of religious belief and attitude to organ donation may therefore be useful in exploring this in greater depth.

Furthermore, Morgan et al found that those who opposed donation on religious grounds expressed uncertainty as to why this was. This suggests that negative attitudes may have more to do with general discomfort, uncertainty about religious stance, and lack of knowledge around the matter, rather than interpretations of religious teachings. Indeed, uncertain individuals expressed a desire to find out more information from their faith leaders about the issue. This suggests that there may be a need for more clarity from faith leaders about the position of the Christian faith on the issue of organ donation.

The importance of the relationship one has with God has also been evidenced in research conducted by Davis and Randhawa (2006)⁵ among the Black African and Black Caribbean population in the UK. It has been suggested that religious beliefs are more likely to be cited as a negative barrier to organ donation among these groups (Randhawa et al, 2010^{a,b}). However, evidence suggests that the strongest barrier to donation is not perceived religious impermissibility but how the individual interpreted his or her own relationship with God, particularly in times of sickness. The common response to illness was that it was God's will and their response would be to accept this. Furthermore, the majority of participants also expressed a desire to remain whole after death due to expectations of being resurrected in the next life and the need for their organs then. These issues were also important for those who expressed no religious belief, indicating the role religion can play through its influence on the values and beliefs of the family and the wider community. Cultural factors whereby discussing death is generally considered taboo were also discussed, as well as a general lack of knowledge about the donation process, and fears of family disapproval or rejection should they decide to become a donor (Davis and Randhawa, 2006).

Overall, both Sanner's (1994) and Davis and Randhawa's (2006) research suggest that religion can play a decisive role in terms of forming attitudes to organ donation but not necessarily in obvious ways. This may be especially true within more Protestant cultures (including Pentecostalism), given Protestantism's focus on the relationship between the individual and God, rather than this relationship being mediated through the Church as it is in Catholicism (Cohen and Hill, 2007). Therefore interpretation of faith and one's relationship with God in countries that have been heavily influenced by Protestantism (northern Europe) arguably interplay with other cultural and

⁵ Qualitative research exploring the influence of religion among Black African and Black Caribbean population in London. The majority of the participants were Christian, however some groups were mixed consisting of Christians, Muslims and those professing no faith but brought up in religious households.

social factors in terms of influence on attitudes towards organ donation, making the influence of Christianity difficult to unpack.

3.3 Bodily integrity as a barrier to organ donation

Ideas about how the body should be treated after death is another theme apparent in much of the evidence. Research conducted by Morgan et al (2006) in the UK investigated knowledge and attitudes to kidney donation among BME groups, with a focus on Black African and Black Caribbean individuals. The study found that the belief in the need for bodily integrity was more common across BME groups, and remained so even after religion was accounted for. Although detail is not given in relation to how this differed among different religious groups, the majority of individuals in the survey sample were Christian (White, Black Caribbean, and Black African).

Further research into how much the belief in the need for bodily integrity is related to religious or cultural beliefs may therefore be useful. On the whole, Black African and Black Caribbean respondents were more likely to display less favourable attitudes to organ donation, being significantly less likely to be willing to donate, or to have discussed organ donation with their family. They were also significantly more likely to oppose an opt-out system for organ donation. In terms of the role of religion, while the majority of respondents believed that donating organs was acceptable to their religious beliefs, religion was more likely to be a significant barrier among Black African and Black Caribbeans than Whites, with its effect remaining statistically significant after adjusting for religion and ethnic group. Further barriers to donation common to all ethnic groups, but more prevalent among Black African and Black Caribbean respondents, were medical mistrust and the belief that registering as a donor may tempt death (Morgan et al, 2006). This research shows that religious beliefs are more likely to be cited as a barrier to donation among BME groups, although its influence overall is difficult to unpack given the multiple barriers to donation identified in this research.

Sanner's (1994) research conducted in Sweden found that the belief that the body should remain intact after death and the emphasis placed on showing respect for the deceased individual were commonly cited barriers to donation. Cutting the body was perceived as a violation, with interviewees fearing that the body could still feel pain. These beliefs regarding bodily integrity were expressed regardless of overall attitude towards donation. In relation to issues directly concerning religious or spiritual beliefs, the research found that:

- Anxiety about offending God or Nature was the most commonly referred to, with the belief that organ donation conflicts with the belief that one should respect the limits set by God.
- This anxiety was more prevalent among those with negative attitudes to organ donation, indicating that this may be one of the factors which influence religious individuals' attitudes to organ donation. Individuals drawing on this argument were also more likely to display low levels of

ambivalence towards organ donation, indicating that their attitude may be unlikely to change with more information advocating donation.

- The perception that organ donation may delay a funeral and prevent it from going ahead in a traditional way was also commonly expressed. This also links strongly to the emphasis that was placed on protection of the value of the individual through bodily integrity and respect for the dead.

Overall, participants in the research tended to draw on both positive and negative motives for organ donation. This ambiguity perhaps explains why there tends to be a discrepancy between attitude and behaviour in relation to organ donation, for example why those of faith may in theory support donation but in practice be unwilling to consent to organ donation. This research offers some interesting insights into barriers to donation, including particular ideas which are arguably grounded in religious and socio-cultural beliefs about death and the body.

3.4 Interplay of religious and cultural beliefs

Most of the research identified is inconclusive, showing both positive and negative correlations between Christianity and attitudes to organ donation (Sanner, 1994; Rumsey et al, 2003; Morgan et al, 2008). In order to gain more of an insight into how religious belief in general influences willingness to donate, Stephensen et al's, (2008) research⁶ attempted to unpick its role by considering it alongside religiosity, religious norms (the practices and values prescribed by one's religion), subjective norms (the norms and values of those closest to you), bodily integrity and attitude to donation. The study found no significant correlation between religious norms and intention to donate; and no significant correlation between religiosity and intention to donate. However, belief in bodily integrity had a significant negative influence on willingness to donate, and a significant effect on religious norms.

This supports the findings of Sanner (1994) and Morgan et al (2006) where beliefs about bodily integrity transcend religious norms, with those who strongly value the importance of bodily integrity tending not to support organ donation regardless of awareness of religious norms (views of their faith, or faith leader). The interplay between religious and cultural beliefs may therefore be an influencing factor. Subjective norms (the perceived beliefs of those closest to you) were found to positively correlate to signing the donor card.

Thus, in this particular study both religious norms and religiosity were not found to have any significant positive or negative relationship to willingness to donate, whilst subjective norms were. Although this research provided data based on relatively large sample size compared to the other studies in this field, all data were gathered through convenience sampling on university

⁶ The research involved a convenience sample survey across six university campuses in the US, with a total of 4,426 respondents.

campuses (with a predominantly young adult and White population) and therefore cannot be generalised to the population as a whole. Religious norms and religiosity may therefore be more of an influencing factor in other socio-demographic groups as other research suggests (Stephenson et al, 2008).

Although not explored in the study by Stephenson et al (2008), the influence of subjective norms may also include religious norms/religiosity as influencing secondary factors. For example, an individual whose family is highly religious, yet not highly religious him or her self, may fear that the views of his or her family on organ donation may differ from theirs thereby impacting on willingness to donate. This may be particularly important among ethnic groups where the role of the Church is still central in the community and likely to be an influencing factor in forming attitudes and values, as indicated in UK research (see Davis and Randhawa, 2006).

The influence of social norms has been shown to be particularly influential among African Americans in the United States. For example research conducted by Morgan (2006) found that willingness to donate among African Americans was more likely to be associated with knowledge, attitudes and social norms than demographic factors such as age and level of education. Furthermore, religiosity, bodily integrity and medical mistrust were also important factors (Morgan, 2006). Barriers to donation among African Americans are therefore multifaceted, making it difficult to fully untangle the role of subjective/social norms and religious norms given the close kinship relations and the influence of the Church historically within African American communities (Arriola et al, 2007). What this suggests is that regardless of how much religion features as a barrier to donation, the clergy could play more of a role in informing members of the African American community about organ donation.

Qualitative research conducted among African American clergymen by Arriola et al, (2007) found that clergymen were reluctant to talk about donation, despite awareness of the need for organs among their community and personal agreement with organ donation. This was because they felt they did not have adequate knowledge to inform congregations, and had fears of being viewed as interfering. They also questioned their influence in light of increasing secularisation (Arriola, et al 2007). However, given the importance of social norms and religiosity among African Americans in Morgan's (2006) study, community based campaigns that include an active role played by the church could be used to ensure accurate knowledge and information to dispel some of the myths surrounding organ donation, although efforts need to be made to ensure faith leaders are adequately informed. Campaigns at this level are more likely to encourage discussion about organ donation, this may help to increase knowledge and awareness, and make discussion of organ donation with next-of-kin more the norm, having a potential positive influence on consent (Morgan, 2006).

3.5 Survey of Christians living in Wales

As part of the communications strategy for the implementation of the Human Transplantation (Wales) Act, the Welsh Government has commissioned an equality and diversity training company, Cognition Associates, to engage with different faith and BME communities across Wales to promote discussion of organ donation, and facilitate understanding of the new law. This work has involved interviewing faith and BME representatives and organisations, and developing a strategy for engagement work with members of the communities, for example by visiting places of worship and promoting discussion of the issue.

While this engagement work is helping to aid understanding of attitudes towards organ donation and the new law among different faith groups in Wales, little is currently known about the views of Christians. Therefore, a survey was conducted among Christians living in Wales in order to help address this information gap, and to be considered alongside the evidence reviewed as part of this report.

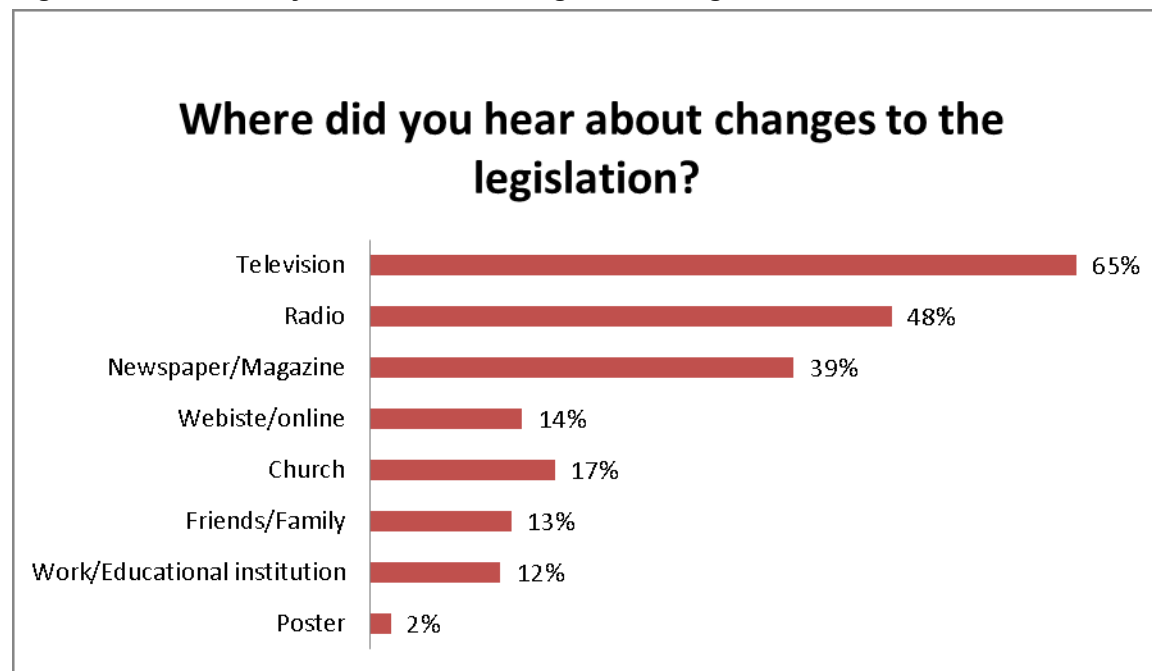
An online survey (see Annex A for questionnaire) was designed to better understand Christian attitudes to organ donation and deemed consent, and to find out whether the views of Christian parishioners mirrored those of their Church leaders on these issues. A link to the online survey was sent to representatives from a number of different churches and organisations across the different denominations in the week running up to Easter 2014. Representatives were asked to circulate the survey link among their congregations. The sample was therefore self-selecting, with responses dependent on both the choices of how the survey was publicised among congregations (for example by email, or parish newsletter), and the decision of individual parishioners to choose whether or not to complete the survey. This method was chosen due to time and resource constraints. The findings, therefore, offer an insight into the views of the Christian population in Wales but should not be considered as representative.

Overall, 116 individuals completed the survey over the one month period (15 April to 16 May) the survey link was available (see Annex B for respondent demographics).

3.5.1 Attitudes to organ donation and presumed consent

Almost all of the respondents (97 per cent) were aware of the new organ donation legislation. Given the self-selecting nature of the sample, it is not surprising that awareness levels are so high, as those with an interest in the topic would be most likely to respond. Changes to the legislation were heard about through multiple sources, although television was the most commonly cited source of awareness (65 per cent), while 17 per cent said they became aware of the change in legislation through church (Figure 3.1).

Figure 3.1: Where did you hear about changes to the legislation? ^a



(a) Total over 100 per cent as respondents could give multiple responses.

In terms of attitudes towards the legislative changes, around six out of ten respondents were in favour, while around two out of ten were against. The remainder said they needed more information to decide or did not know (Table 3.1).

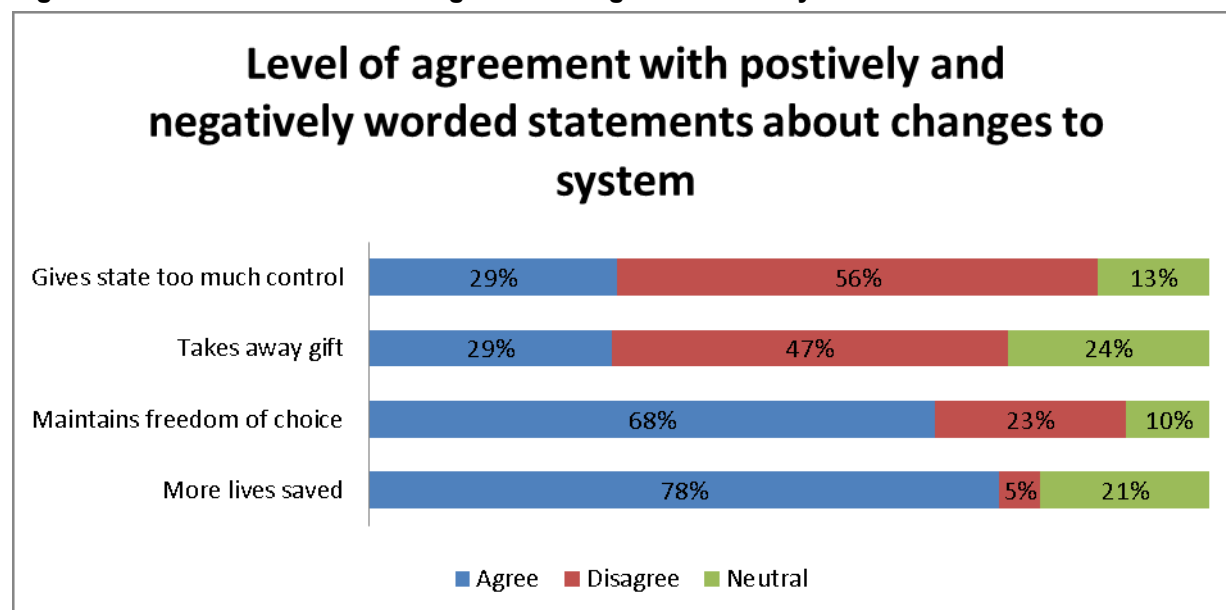
Table 3.1: Which of these statements about changes to the organ donation system in Wales best reflects your view?

| Statements | % |
|-----------------------------------|----|
| I am in favour of the changes | 61 |
| I am against the changes | 22 |
| I need more information to decide | 11 |
| I don't know | 5 |

Respondents were asked the extent to which they agreed or disagreed with positively and negatively worded statements about changes to the organ donation system. The majority of respondents agreed with both of the positively worded statements (that an opt-out system 'maintains freedom of choice' and will 'save more lives'), while around a third agreed with the negatively worded statements (that an opt-out system 'gives the government too much control' and that it 'takes away the gift' of organ donation) (Figure 3.2).

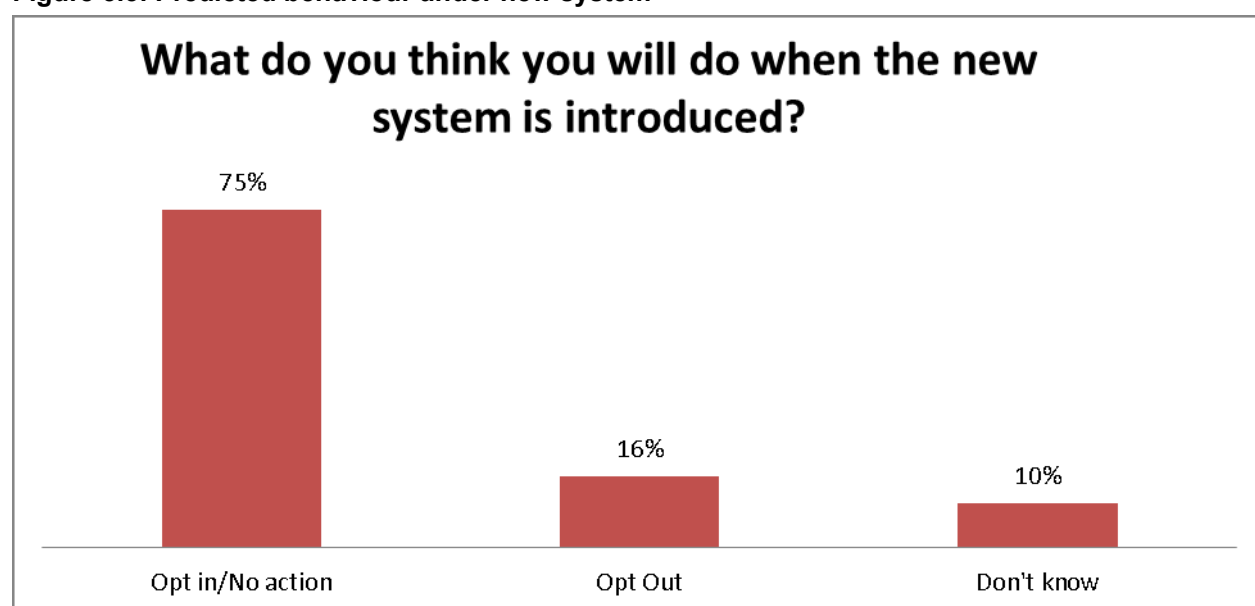
This reflects the overall positive views regarding legislative change expressed by the majority of respondents in this survey.

Figure 3.2: Statements about changes to the organ donation system



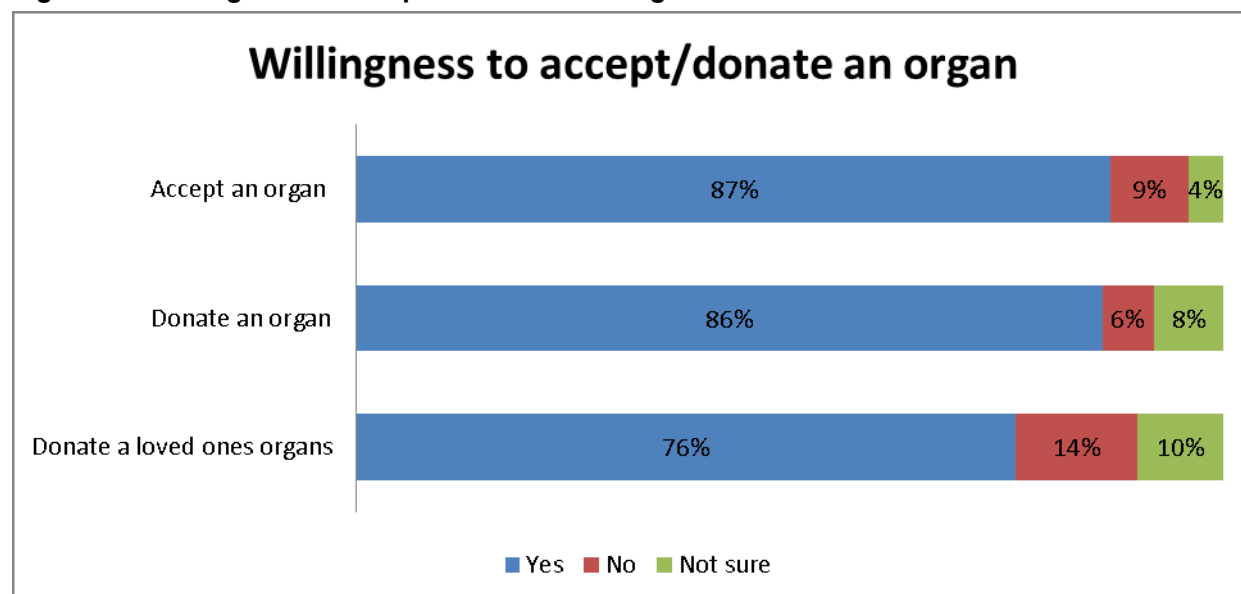
In terms of intended behaviour when the new system is introduced, three quarters of respondents said they would opt in or do nothing, while fewer than two out of ten said they would opt out (Figure 3.3).

Figure 3.3: Predicted behaviour under new system



As might be expected given the positive attitudes to legislative change, the majority of respondents reported a high willingness to accept and donate an organ. Around three quarters (76 per cent) would also be willing to donate the organs of a deceased loved one in cases where they had not opted-out under the new legislation (Figure 3.4).

Figure 3.4: Willingness to accept and donate an organ



The positive attitudes displayed were also mirrored by the high level of individuals already on the organ donor register (57 per cent)⁷.

3.5.2 Perception of denomination and faith leaders' views

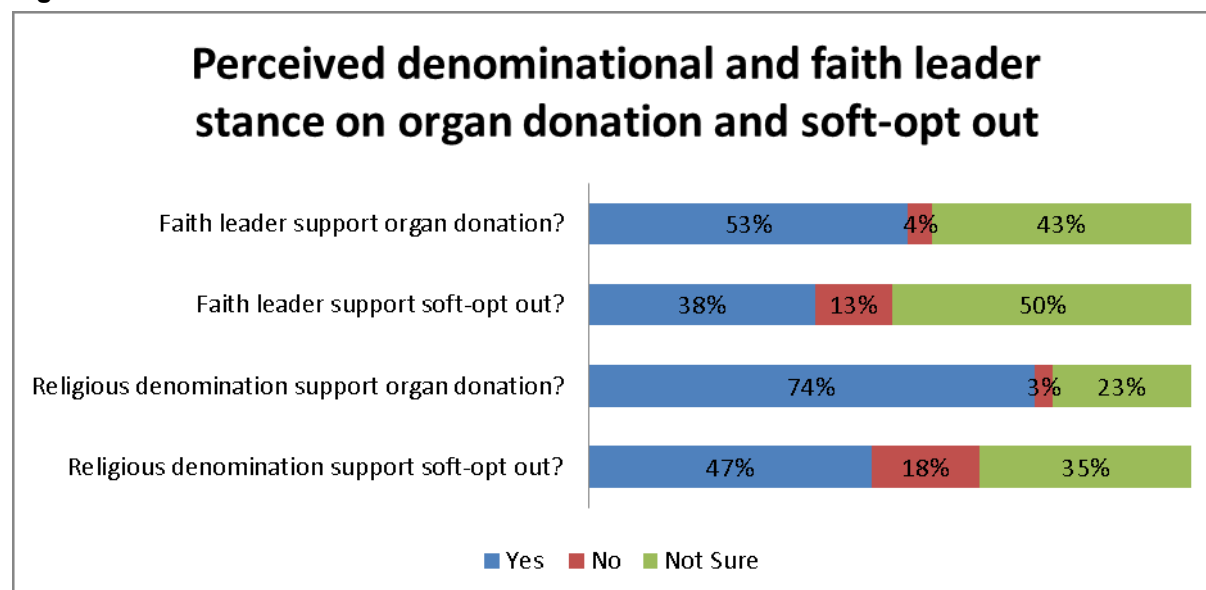
The majority of respondents believed that both their denomination of Christianity, and faith leader (defined as their priest, vicar or pastor), were supportive of organ donation. However, there was more uncertainty with regard to the views of their faith leader, with around four out of ten (43 per cent) saying they were not sure.

Respondents tended to be unsure about both their denominational and faith leaders' views on the soft opt out system. Again, there was more uncertainty about the views of their faith leader than their denominational stance.

Overall, respondents were more certain about the views of their religious denomination than they were about the views of their local faith leader on both matters (Figure 3.5).

⁷ The corresponding figure for the total population resident in Wales is 33 per cent (NHSBT).

Figure 3.5: Perceived denominational and faith leader views



3.5.3 Views from respondents in favour of the change in legislation

Comments from respondents who were in favour of the legislative change drew on both faith related arguments and more individual or pragmatic arguments. Some explicitly referenced their faith as a positive endorser, with others viewing donation as a matter of individual choice. Respondents already on the organ donor register were more likely to be in favour of the legislative change, perhaps indicating the strength of their belief in donation regardless of whether their faith was a motivating factor in this decision.

Respondents who viewed the issues of organ donation and deemed consent as a non-faith related matter tended to refer to arguments of personal choice and pragmatic issues, rather than focussing on their faith:

“I am unaware of what my faith group feels/teaches about organ donation. In any case, it would not change my mind. I have been registered as potential donor for many years.”

Protestant, female, 55+

“To be honest I hadn’t really thought about it from a theological viewpoint. I think if people have the choice, if their faith guides them, the complacency that currently costs lives will be addressed (in my view, as it should be).”

Anglican, female, under 35

“Glad to say that my religious denomination (United Reformed Church) encourages such debate and in general allows individuals to make up their own mind.”

Presbyterian, male, 55+

“I feel that [the opt out system] will make people think about the issue up-front, rather than the present system of being able to avoid it until it matters.”

Anglican, male, 35-54

“The topic has not been discussed but there is a very pragmatic and 'giving' approach to supporting others. Again, the pragmatic approach and imperative to give to others who are suffering would lead me to think that my faith would support this.”

Methodist, female, 55+

Some respondents also attributed negative views towards donation and deemed consent to factors such as age, and lack of information about the donation process. Again, this demonstrates further that the respondents did not necessarily see donation as an entirely faith-based matter. Organ donation was ultimately viewed as a matter of individual conscience, with deemed consent being viewed as a pragmatic way to raise donor rates.

However, positive Christian arguments associated with altruism and creating a better society were also cited as motivating factors for donation. Deemed consent was viewed as way of raising donation rates without undermining individual choice:

“As a Baptist, we have a strong emphasis on individual conscience, so the views of the Baptist Union would not affect my decision [...] I do not really know what my faith's view [on deemed consent] is but I know how highly it prizes life and I see this as one way to use the creativity and resources that God has given us in order to increase the quality of life.”

Baptist, female, 55+

“I have no problem with [deemed consent] as a practising Christian. Many people just don't like to think about death so don't think of organ donation. This helps them do that.”

Anglican, female, 35-54

“I believe we have been given the gift of life, and to share that gift is a privilege as Christians we can fulfil. [Deemed consent] was unusual to me at first, but I believe there will be those who would have wanted to donate, but never took the chance, and if they can give the gift of new life for someone in need, then it is all good.”

Methodist, female, 55+

Those stating an explicitly faith related view tended to draw on the Christian motives of altruism and ideas about death in order to support organ donation and the legislative change:

“Jesus said to love your neighbour as yourself, so I honestly can't see why any Christian could be against organ donation”

Anglican, female, under 35

“As a Christian I believe that the soul leaves the body on death, so the body is just an empty vessel and if parts can be used to help others to live that is to the good. I have my views, but those who really feel strongly about donations should have the opportunity to opt out.”

Anglican, female, 55+

There were also a number of individuals aware of their church or faith leaders' opposition to deemed consent who took the opportunity to voice their disagreement:

"Contrary to the stated views of [my church], I personally have no problem in reconciling my faith and my longstanding and heartfelt view that organ donation is a good thing and that the soft opt-out system would increase the number of donors. I feel sure that many people simply don't get round to registering as donors, despite being quite willing to be donors."

Anglican, female, 55+

"I don't know why [my church] is becoming involved with the issue of organ donation. I would have thought they wish to alleviate people's suffering, and promote selfless acts [...] The gift of life is precious, and I feel God would have no problems with transplant."

Anglican, female, under 35

"The Christian faith should support all organ donation. I strongly disagree with [my Church's] comments on the new legislation. They are not helpful and may result in more people opting out of organ donation"

Anglican, female, 55+

3.5.4 Views from respondents against the change in legislation

The majority of comments from respondents who were against changes to the organ donation system were grounded in concerns about deemed consent undermining individual choice, and giving the state too much control. A few concerns were also raised in relation to mistrust of IT systems and medical staff. Donation tended to be viewed as an individual choice and not faith related, although the Christian faith was acknowledged to provide ethical guidelines.

Most respondents against the legislative change were also either unwilling to donate, or uncertain about donation, and therefore stated that they would opt out when the new legislation comes into force:

"I do not know what my faith's views are. I expect that they are multitudinous being as I am an Anglican! My view is [deemed consent] gives too much power to government. Knowing the inadequacies of computer systems, there is no guarantee that registering to opt out will be accessible to medics when needed to be checked, nor that it will be reliably recorded in the first place."

Anglican, female, 55+

"I don't think my faith group would have a single view on the soft opt out system. As an individual Christian I am uneasy about a system which I believe many people would not know existed."

Christian, male, 55+

"Our objection is not to organ donation; it is to the amount of control that this measure gives to government over the bodies of individuals"

Protestant, male, 55+

There were also some respondents who were either already on the donor register, or stated they would be willing to be a donor, who also opposed the legislation on similar grounds:

“Organ donation is good. The state making decisions for us, and assuming control of our bodies, is not.”

Anglican, male, 35-54

Comments that the legislation undermines the gift virtue were also made in conjunction with arguments about individual choice by respondents who were either unsure about what they will do when the new legislation comes into force, or stated that they would opt-out:

“I did object in writing when this legislation was first suggested, on the grounds that no-one has a right to my body when I die, it belongs to me and my family.”

Anglican, female, 55+

“Presumed consent is wrong – choice and the freedom to choose is part of the Christian message and the individual's right to choose is part of that and should be respected.”

Anglican, female, 55+

3.6 Summary

Overall, there is little in the way of conclusive evidence regarding the role of the Christian faith in terms of its influence on willingness to donate.

Evidence shows variations in both attitudes towards donation and family refusal rates regardless of the consent system in place, with the influence of faith not being explored in the large survey data. In-depth qualitative research among localised populations indicates that the interplay of culture and religion is perhaps more pertinent – for example, in beliefs about bodily integrity that may be more cultural than religious.

In terms of the direct influence of the Christian faith, it is more likely that strength of religious belief and interpretation of individual relationship to God, rather than the teachings of the faith, make up one of the many factors that influence attitudes towards organ donation. Research suggests that high levels of religiosity and beliefs about bodily integrity may act as barriers to donation, rather than the influence of religious teachings.

The role of religion was also found to be more influential among minority ethnic groups, albeit as part of a number of other important factors. These barriers are mirrored in numerous pieces of research conducted on organ donation among ethnic minority groups in multi-ethnic societies, regardless of the religion or consent system.

Little is known specifically about the attitudes of Christians to presumed consent, although church leaders in Wales have publicly opposed presumed

consent due to the belief that it undermines individual choice and the gift of life virtue (NHSBT, 2013c; Stack et al, 2012). Research amongst faith leaders by Randhawa et al (2010b) also shows that Christian faith leaders tend to be pro-organ donation, yet opposed to presumed consent.

Respondents to the survey of Christians in Wales tended to see organ donation as a matter of individual choice. Many respondents viewed the new legislation as a pragmatic means to raise donation rates. Explicit faith arguments in favour of legislative change tended to draw on arguments about altruism, the greater good and beliefs about death which stress that the soul leaves the body on death. These arguments could equally be interpreted as pragmatic; but respondents grounded them in their faith beliefs.

Those against legislative change tended to be so on the grounds that it gives the state too much control, rather than being based on religious beliefs. Given that the majority of the respondents against the legislation were not registered as donors, or sure they would be willing to donate, it would be interesting to conduct further research to explore whether these negative attitudes towards deemed consent were in part due to uncertainty about organ donation in general.

Overall, the findings from the survey cannot be generalised to the wider Christian population living in Wales due to the self-selecting nature of the sample. A noticeable gap here is that there were no Catholic respondents to the survey. However, this survey has provided an insight into how some Christians in Wales view organ donation and deemed consent, and the role played by their faith (and faith leaders) in forming these views, with the Christian faith arguably being a motivating factor for some in donation decisions.

4. Research exploring the role of Islam in organ donation

This chapter brings together research investigating the relationship between Islam, organ donation and presumed consent. Most of the research identified was conducted in Europe (mostly in the UK) and across predominantly Muslim countries.

4.1 Research conducted in the UK

Much of the research considering the role of Islam in organ donation in the European context has been conducted in the UK. The majority of Muslims in the UK are of South Asian descent, although the UK also has Muslim communities from regions of Africa, Malaysia and the Middle East, with the majority being practising Sunnis (Ansari, 2002).

In the UK, individuals of South Asian origin represent 15 per cent of those waiting for a kidney transplant whilst only comprising four per cent of the UK population, leading to inequality in access to organs (Randhawa, 2011). This is further compounded by South Asians being less likely than the rest of the UK population to register as organ donors – representing one per cent of those on the register (Rudge et al, 2001 cited in Randhawa, 2011) – and having higher rates of family refusal (NHSBT, 2013^b). Efforts to address this are present in current and previous organ donation strategies (DofH, 2008; NHSBT, 2013^c), and research has been conducted among South Asians in an attempt to understand and address the barriers to donation among this group.

Research among BME groups in the UK has found a strong association between the Muslim faith and concerns about organ donation (Davis and Randhawa, 2006; Morgan et al, 2006; Karim et al, 2013). This is mainly due to uncertainty about the permissibility of organ donation in Islam. For example, Karim et al (2013) conducted an attitudes survey among South Asians. Their study represents one of the few larger-scale surveys conducted among this population in the UK with much of the other research being small-scale, regional, or qualitative in nature. They found that of all South Asians surveyed, Muslims demonstrated significantly less favourable attitudes to organ donation than their South Asian Sikh and Hindu contemporaries (Table 4.1).

Table 4.1: Attitudes to organ donation among South Asians in the UK

| | Muslim (%) | Hindu (%) | Sikh (%) |
|-----------------------------|------------|-----------|----------|
| Agree with organ donation | 60 | 92 | 89 |
| Registered organ donor | 5 | 40 | 26 |
| Compatible with their faith | 40 | 47 | 79 |
| Happy to receive organ | 69 | 75 | 74 |

Source: Karim et al (2013)

These results were also supported by respondents' subjective assessment of factors that explain poor donation consent among South Asians, with religious

guidance being rated as very important by 59 per cent of the whole group. In addition, more importance was given to religion in guiding organ donation decisions among Muslim respondents (70 per cent) than Hindus (28 per cent) and Sikhs (42 per cent). Differences in the influence of religion on donation were also supported by analysis of ethnicity with those of Pakistani or Bangladeshi ethnicity (predominantly Muslim) tending to have less favourable attitudes to organ donation compared with those of Indian ethnicity, suggesting that religion may be the overriding factor dissuading South Asians in the UK from organ donation. Other important factors that featured in the subjective assessment of barriers were distrust of the health system and poor publicity of organ donation.

However, on the whole awareness of organ shortage was relatively high (68 per cent) with a high percentage also knowing someone on dialysis (65 per cent) – both important factors identified as determining a more positive attitude towards donation. This perhaps indicates the challenge where religious concerns may be an overriding factor in determining negative attitudes to donation despite awareness being relatively high. The authors suggest that a deeper and more sympathetic understanding about the specific issues regarding organ donation among Muslims may therefore be necessary (Karim et al, 2013).

4.2 Perceived compatibility of organ donation with Islam

The importance of religion in organ donation decisions among Muslims is also confirmed in other survey data (Sharif et al, 2011). This study aimed to assess the attitudes of Muslims living in Western countries⁸ to organ donation. Table 4.2 (below) summarises some of their findings.

Table 4.2: Attitudes to organ donation of Muslims living in Western countries

| Survey question | Yes (%) | No (%) | Don't know (%) |
|---|---------|--------|----------------|
| Do you agree with organ donation? | 69 | 10 | 22 |
| Do you agree with blood donation? | 91 | 1 | 8 |
| Is organ donation compatible with Islam? | 39 | 18 | 42 |
| Would you receive an organ if required? | 72 | 2 | 8 |
| Do you agree with the concept of presumed consent? | 26 | 55 | 20 |
| Would you overrule somebody else's wishes to donate based on your personal views? | 13 | 66 | 22 |

Source: (Sharif et al, 2011)

Although the majority of the respondents agreed with organ donation in principle, only four out of ten believed it to be compatible with Islam, and a similar proportion said they didn't know. Uncertainty regarding the permissibility of organ donations may therefore be an important factor in terms of barriers to donation.

⁸ Based on analysis of 675 survey respondents residing in Western countries: United Kingdom (59%), Continental Europe (5%), North America (34%) and Oceania (2%).

When asked what influenced their decisions concerning organ donation, respondents cited interpretations of religious scriptures as the most influential. The advice of family and the local mosque or imam was next in degree of influence. Furthermore, in line with the findings in Karim et al's (2013) study, these factors were also cited as factors that may explain poor donation rates among South Asians. Few stated that they would be willing to overrule advice given by the family, local mosque or imam, reflecting the importance religion and the family may play in organ donation decisions.

These findings may also explain why only a quarter of the respondents agreed with the concept of presumed consent, with the majority either being against it or uncertain about it. While there is little other research into this subject, research conducted in the UK by Randhawa et al (2012) found that Muslim faith leaders are generally opposed to adopting presumed consent legislation.

Uncertainty about the permissibility of organ donation within Islam has also been apparent in the qualitative research with apprehension about being a potential donor centring on this issue. For example, Darr and Randhawa's (1999) and Randhawa's (1998) research explored the attitudes to organ donation among Asians living in Luton. Their research found that respondents generally did not know the stance of their religion on organ donation. For the Muslim participants, religious permissibility was central in forming their attitudes and behaviour towards organ donation, with advice from the Ulema on the matter being seen as necessary before making any decision. Of the few participants who believed that they knew what the stance of Islam was on organ donation based on their interpretation of the Qu'ran, some believed Islam was opposed to it while others said it was favourable. Some expressed that if they knew for sure that Islam did not oppose donation, there would be no barrier to donating their organs (Darr and Randhawa, 1999; Randhawa, 1998). Only two of the 32 Muslim participants had heard of the fatwa passed by the Muslim Law Council in 1995, illustrating the lack of awareness of the religious stance, and that public campaigns to raise awareness of the passing of this fatwa may have had little impact (Randhawa, 1998).

Despite there being the many fatwas passed in Muslim countries allowing both living and cadaveric organ donation (El-Shahat, 1999; Sharif, 2012), there is still public resistance to organ donation in some countries largely due to religious concerns (Mousavi, 2006). Indeed, the majority of donations in the Middle East are from living donors. Data from countries that are members of the Middle East Society for Organ Transplantation (MESOT) shows that there is huge potential for improved donation rates in these countries, but this is stunted due to a number of factors. End stage renal failure is not prioritised in many MESOT countries due to the limited resources available for transplant infrastructure. As well as transplant systems being poorly resourced, substantial barriers also exist in relation to religious concerns, especially regarding the concept of brain death which is still heavily debated in the medical community; and is either not legally recognised or fully implemented in Egypt, Morocco, Sudan, Syria and Libya. Low levels of public awareness

regarding the importance of organ donation also limit potential donors (Shaheen, 2009).

Given the different views within Islam regarding organ donation and the fact that transplantation procedures are relatively new in most Muslim countries, it is not surprising that presumed consent is not the norm. Turkey is an exception to this, with presumed consent included in the amendments to its 1979 Act in 1982 in cases where the deceased individual's relatives cannot be contacted (Haberal, 2008). Therefore the majority of deceased donation in Turkey is still dependent on expressed consent, with the family having power of veto (Rosenblum, 2012). Reflecting this, deceased donor rates are still relatively low (4.6 PMP), with high family refusal rates (77 per cent) (Council of Europe, 2013), with the majority of donations being from living donors. Attitudinal surveys suggest that public opinion regarding willingness to donate is positive (between 50 and 60 per cent) but this is not reflected in the number of individuals on the organ donation register and the high rate of family refusal (Bilgel et al, 2006).

This is the case across many Muslim countries, despite the majority of fatwas sanctioning donation (El-Shahat, 1999), with consent rates for deceased donation tending to be lower than in European countries (Table 4.3).

Table 4.3: Donation rates in selected countries

| European Countries | PMP | Muslim Countries | PMP |
|--------------------|------|------------------|-----|
| Italy | 21.6 | Iran | 4.1 |
| France | 23.4 | Saudi Arabia | 3.9 |
| UK | 15.1 | Qatar | 2.4 |

Source: Gomez et al, 2010

4.3 Organ donation and bodily integrity

As found in other studies (see Sanner, 1994; Morgan et al, 2006) respondents across all three faith backgrounds (Muslim, Hindu and Sikh) raised commonly expressed fears about being 'carved up', mistrust of doctors, not really being dead when donation takes place, and a general unease about the thought of their organs being in someone else's body. These beliefs were common among all respondents so are arguably more cultural in nature (Randhawa, 1998). However, issues pertaining to bodily integrity were particularly important among Muslims. A small scale study of Muslim graduates by Aslam and Hameed (2007) supports this, with delays to the funeral and bodily integrity being cited as the two major reasons for not considering deceased donation.

The need for bodily integrity is also cited as a barrier in Alkhawari et al's (2005) qualitative research among Muslims living in west London. Islamic burial rituals maintaining that the body be treated respectfully and the burial carried out as soon after death as possible, coupled with beliefs that the body is owned by God, were expressed frequently as reasons for unwillingness to donate. Views about bodily integrity were considered so important that some

participants stated a wish to die at home in order to avoid medical professionals interfering with their bodies. Consistent with other studies (see Karim et al 2013), participants also expressed a negative perception of the health care system, including the belief that professionals did not respect these beliefs and treat cadavers properly, potentially acting as a further barrier to organ donation among Muslims (Alkhawari et al, 2005). Campaigns to raise awareness about organ donation may therefore benefit from tackling misconceptions about the donation process (Darr and Randhawa, 1999).

Lack of acceptance of brain death may also act as a significant barrier to donation in Muslim countries due to it still being a contested issue among scholars (Shaheen and Souqiyyeh, 2004). For example, some scholars in Saudi Arabia are reluctant to allow organ donation from brain dead donors despite Islamic jurisprudence acknowledging it as legal death.

The socio-political context in which organ donation takes place may also act to further compound barriers relating to religion and bodily integrity. For example, the illegal trading of organs is common across Asia due to poor levels of public healthcare, high levels of income inequality and high demand for organs and may encourage negative perceptions of organ donation (Vathsala, 2004; Bagheri, 2005). Indeed fear of organs being trafficked was found to be a barrier to donation in Siddiqui et al's (2012) research, with high levels of medical mistrust centring on fears that doctors may profit from selling organs, reducing public trust in the health care system as a whole. Over two thirds of respondents in this research also felt that the government could not run a transplant system fairly (Siddiqui et al, 2012). This shows that even healthcare professionals may not trust their own healthcare institutions, potentially acting as a significant barrier to organ donation. Lack of awareness about the legality of organ donation may also have contributed to the negative attitudes displayed among medical students in Pakistan (Siddiqui et al, 2012; Feroz Ali et al, 2013).

4.4 Role of the family

The family has also been cited as an important influencing factor in organ donation decisions. In Darr and Randhawa's (1999) research, the majority of respondents were unwilling to give permission for donating the organs of a deceased family member whose wishes were not known. If such a decision were to be made, it would be a decision taken by the whole family. Research by Gauher et al (2013) also supports this, with all participants (including Hindus and Sikhs) stressing the importance of the decision being a family one. This has implications for presumed consent in cases where the wishes of a deceased individual are not known. Illustrating this point further, in Alkhawari et al's (2005) research almost all of the older participants said they would not allow anything to be done with their children's bodies after death, or allow their children to sign the donor register. The approval of the most senior male member of the family was also considered particularly important. A general objection to presumed consent was therefore expressed by participants in this research.

Given the importance placed on the role of the family evident in these studies, it is perhaps more important within Muslim communities that communication is encouraged within both the family and in the community more broadly to ensure that the wishes of the individual are known. Indeed, the fact that most knowledge and awareness regarding organ donation was found to come from television, the local radio, or knowing someone in the community affected by organ donation, lends support to the potential for community networks being useful in raising awareness. The use of kin-networks has been supported in other health research in the Pakistani community where kin relationships were found to be an important source of culturally sensitive information in health matters (see Darr, 1990 cited in Darr and Randhawa, 1998; Khan and Randhawa, 1999). The authors therefore recommend a multi-source approach in terms of ensuring people have access to enough information about organ donation.

4.5 Awareness of religious views on organ donation

The findings from Randhawa's (1998) research support what was found by both Karim et al (2013) and Sharif et al (2011) with indecision and unwillingness to donate tending to be connected to uncertainty regarding religious stance, and a general lack of knowledge regarding the donation process. Barriers also exist in relation to bodily integrity (Randhawa, 1999; Aslam and Hameed, 2007; Alkhawari et al, 2005), and mistrust in the medical system (Darr and Randhawa, 1998; Randhawa, 1999; Alkhawari et al, 2005; Karim et al, 2013). Furthermore, the survey data also indicate that despite more public campaigns, not much appears to have changed in terms of awareness of religious stance. More may need to be done to engage with Muslim communities, especially given the wide spectrum of views on the matter (Karim et al, 2013; Sharif et al, 2011).

Indeed, reflecting the divergence of opinion within Islam, research has also suggested that it is the belief that organ donation is impermissible under Islam that acts as a barrier to donation. For example, the majority of participants in Alkhawari et al's (2005) research believed Islam opposed organ donation based on interpretations of the Qu'ran and beliefs about bodily integrity (Alkhawari et al, 2005; Gauher et al, 2013). Research by Raziq and Sajad, (2007) also supports this, which found that many Muslims believe organ donation to be impermissible in Islam, and very low awareness of any fatwas passed on the matter, consistent with earlier and more recent research (Randhawa, 1999; Aslam and Hameed, 2007; Gauher et al, 2013). This perhaps indicates that these fatwas hold little influence over Muslims in the UK. Indeed, in Sharif et al's (2011) research it was the interpretation of religious texts, and the advice of the local Mosque or imam that were viewed to be the most important in donation decisions, rather than knowledge of fatwas. It should be noted that the fatwas discussed in Raziq and Sajad's (2007) study⁹ may have had little relevance to the participants, who were of predominantly Pakistani and Bangladeshi ethnicity. Many participants in

⁹ The UK Islamic Law council, the Shariah Academy of the Organisation of Islamic Conference, the Grand Ulema Council of Saudi Arabia, the Iranian Religious Authority, and the Al-Azhar Academy of Egypt.

Razaq and Sajad's (2006) research said they were unlikely to donate their organs, even if they knew for sure that organ donation was permissible.

The research so far suggests that organ donation may not be seen as important and is not discussed by religious leaders. Given the importance of the advice of imams in informing individual conduct (Alkhawari et al, 2005; Sharif et al 2011), this lack of discussion may serve to reinforce beliefs that organ donation is not an important issue. Engagement could therefore be sensitively tailored in response to these particular cultural and religious issues as a desire for more information was also expressed by respondents in some of the research (Darr and Randhawa, 1999; Aslam and Hameed, 2007; Karim et al, 2013). For example, students in Aslam and Hameed's (2007) research suggested campaigns in local schools, communities and mosques, success stories in Asian television dramas and movies, and religious lectures in local mosques.

In light of these findings, faith leaders have been identified as being able to play a key role in raising awareness of the importance of donation and promoting discussion about organ donation (Department of Health, 2008; Randhawa et al, 2012). However, the success of such a strategy is also in part dependent on the views of imams. Research on the attitudes of faith leaders towards organ donation is also mixed in its findings. While the majority of participants in Alkhawari et al's (2005) study had not spoken to imams about organ donation, some participants said they cancelled their donor cards following advice from the imam.

In contrast, Randhawa et al (2012) found representatives from UK Muslim faith organisations supportive of organ donation. However, interviewees also stressed the divergence in opinion within Islam and were reluctant to speak on behalf of the entire Muslim community. They attributed negative attitudes to positive interpretations by scholars not filtering down to the grassroots level. They believed this was partly due to barriers to donation being cultural rather than strictly religious, such as beliefs about bodily integrity. The representatives believed more engagement is needed with authorities and at grassroots level, via mosques or religious centres, to highlight positive Islamic interpretations of donation. The representatives favoured an opt-in system of consent, due it being perceived to respect free choice.

However, Karim et al (2013) recommend caution when adopting a faith leader approach, due to what they perceive to be the possible absence of faith leaders who can legitimately claim to represent the interests of their communities. Similarly to Darr and Randhawa (1999) and Khan and Randhawa (1999), they suggest a grassroots peer education model being adopted. Furthermore, the lack of awareness of organ donation illustrated in the evidence base may, arguably, also reflect lower average socio-economic positions of some BME groups, particularly those in the most deprived and hard-to-engage communities in the UK, lending more support to a grassroots approach (Randhawa, 2011). Although South Asians represent the predominant ethnic group of Muslims in the UK, given the influence of other socio-cultural factors and the diversity of beliefs within Islam, more needs to

be known about the views and beliefs of Muslims from other ethnic groups to tailor campaigns accordingly (Randhawa et al, 2012).

4.6 Attitudes to presumed consent systems

Little research has been conducted on Islam and organ donation in presumed consent countries in Europe, or in predominantly Muslim countries in Asia. However, evidence suggests that individuals from BME groups in Europe tend to display higher levels of refusal, with religious and cultural reasons thought to be the reason for this (Frutos et al, 2005; Lopez et al, 2012). Consistent with what is known in the UK, consent for donation from families in both Spain and France tends to be lower among minority groups, and again, religious and cultural reasons are thought to be the reason for this. Lesoeurs et al (2009) found that transplant coordinators felt ill-prepared to communicate with migrant families about donation due to their own lack of knowledge and awareness about religious and culturally sensitive issues, resulting in miscommunication and misunderstandings which arguably contribute to higher refusal rates. Addressing this through training transplant coordinators may also help to improve trust in the medical system (Lesoeurs et al 2009).

Research conducted in Saudi Arabia by Hammami et al (2012)¹⁰ attempted to find out the preferred form of consent in the Saudi population. Their research found that the majority of respondents were supportive of organ donation, with mandated choice being the preferred choice of consent system, and presumed consent being the least preferred choice. The research did not explore the reasoning behind the ranking of choices so it is difficult to ascertain why presumed consent was viewed so unfavourably but the authors speculate that it may be due to distrust of the medical system and fears about bodily mutilation. Also worthy of note is the Islamic emphasis on intention and will in action, the preference for mandated choice would support this as it acts to ensure wishes are known by making individuals make a decision. This was also reflected in research with Islamic faith leaders in the UK (Randhawa et al, 2012).

Also worthy of note is Singapore which is both the only Asian country to have presumed consent in place and the only country to have a fatwa ruling for Muslims to be included in a presumed consent law. Muslims were initially excluded from the presumed consent legislation in 1987 Human Organ Transplant Act (HOTA), due to needing the consent of two wari's (family members) for organ donation to go ahead. Muslims were still allowed to donate voluntarily, and were encouraged to do so, with MUIS (the Islamic Religious Council of Singapore) conducting a pro-donation campaign distributing pamphlets in mosques. Whilst donation rates improved, it still was not enough to address the organ shortage in the Malay population. The impact of Muslims not being included in the Act was detrimental due to their over-representation on the transplant waiting list¹¹ and non-pledgers being accorded a lower priority than those who were included in the HOTA (Zainal,

¹⁰ Based on a convenience sample of 698 adults at an outpatient clinic.

¹¹ Malays represented 21 per cent of the donor waiting list in 2007 despite only making up 13 per cent of the population (Zainal, 2012)

2012). This resulted in numerous campaigns for Muslims to be included in the Act from 1993 onwards. Following public consultation it was decided that Muslims were to be included in the 2008 HOTA following the ruling of a fatwa in the same year allowing Muslims to be included (Kwek et al, 2009; MUIS, 2013). This fatwa has a strong argument favouring donation stating the benefits of Muslims being included in the HOTA and stressing the particular need for organs among the Muslim population. It also urges faith leaders to advise individuals with the best interests of the community in mind and for those who do not wish to donate their organs to make their wishes known (MUIS, 2013).

Available evidence suggests that the introduction of presumed consent in Singapore has led to deceased donor kidney transplants rising from 4.7 per year from 1970 to 1988 to 41.4 per year from 1988 to 2004, suggesting that this legislation may have helped to overcome cultural barriers to donation among Asians. However, donation rates remain low compared with other developed countries (Vathsala and Chow, 2009). Kwek et al, (2009) argue that presumed consent has not yielded the increase in donors and transplantable organs expected. They attribute this to ICU staff not identifying brain dead patients early enough and a reluctance to broach the issue of donation with family members. They suggest that this is due to a cultural antipathy towards organ donation, stemming from cultural ideas about death and the body being buried whole.

4.7 Views of health professionals

In order to reduce the barriers to deceased donation in Muslim countries, it has been suggested that health professionals could play an important role and should be included in educational strategies to improve donation to equip them with the tools to do this (Shaheen and Souqiyyeh, 2004). However research conducted among medical professionals has found that attitudes towards organ donation do not necessarily differ that much from the public as a whole, making this a challenging task. For example, Bilgel et al's (2006) survey of medical students in Turkey found that despite the majority having good knowledge about organ donation and brain death, confidence in knowledge of the transplant process was less so, with over half believing their knowledge to be insufficient or having no knowledge. Attitudes to deceased donation are displayed in Table 4.4 (below).

Table 4.4 Attitudes to deceased donation among medical students in Turkey

| Willingness to donate | Own organs | | Relatives' organs | |
|---------------------------------------|------------|----|-------------------|----|
| | N | % | N | % |
| Yes, without any hesitation | 70 | 17 | 51 | 13 |
| Yes, but needed persuasion | 169 | 41 | 112 | 27 |
| Do not know | 77 | 19 | 130 | 32 |
| No, absolutely not | 93 | 23 | 116 | 28 |
| Reasons for not donating | | | | |
| Organs could be wasted | 9 | 10 | 10 | 9 |
| Don't want to be cut into pieces | 26 | 28 | 30 | 26 |
| Religious beliefs | 8 | 9 | 14 | 12 |
| Fear of organ harvesting before death | 14 | 15 | 4 | 3 |
| Other reasons | 19 | 20 | 36 | 31 |
| No reason | 17 | 18 | 22 | 19 |

Source: Bilgel et al (2006)

Interestingly, religious beliefs did not play the most significant role in terms of barriers to donation, supporting research conducted among religious officials by Turkyilmaz et al, (2013)¹², although religious permissibility has been found to be a barrier to donation in similar survey research conducted in Turkey (Ozdag, 2004; Naçar et al, 2009). Fear about the body being cut up was found to be the biggest barrier to donation, a view reflected in other research among Turkish medical students by Tontus et al (2011). This relates to particular Islamic beliefs regarding bodily integrity, but has also been shown to be important regardless of religious belief in other studies (Sanner, 1994; Morgan et al, 2006).

The results from Bilgel et al's (2006) research supports other research that has been conducted on attitudes to organ donation in Turkey among both health professionals (Topbaş et al 2005; Tontus et al, 2011), and the Turkish public (Akgün et al, 2002; Ozdag, 2004) with around 60 per cent in this study being willing to donate their organs after death. Therefore the positive overall attitude to organ donation is not reflected in willingness to donate (Bilgel et al, 2006). The fact that medical professionals are potentially leaders in promoting positive donation action suggests that more needs to be done to improve awareness and attitudes to equip professionals to better inform the public on the issue of organ donation, as knowledge about organ donation did not appear to correlate with having a more positive attitude to organ donation.

Although concerns about religious permissibility were not found to be the primary barrier in the Turkish research, religious permissibility has been found to act as a barrier to donation in much of the research conducted in other Muslim countries. For example, research conducted in Pakistan by Feroz Ali

¹² Survey of 550 religious officials in Turkey.

et al, (2013)¹³, and Siddiqui et al, (2012)¹⁴ among medical students, found that lack of knowledge about religious permissibility was the major barrier to willingness to donate in both their respective pieces of research. Similarly to the medical students in Bilgel's, (2006) Turkish study, Pakistani medical students displayed high levels of knowledge regarding organ donation, yet attitudes towards donation were mixed. This was largely attributed to concerns around religious permissibility. Similar findings regarding the significance of the impact of religious permissibility on willingness to donate were also apparent in earlier research in Pakistan (Saleem et al, 2009)¹⁵. This also supports research in Saudi Arabia, which found that Islamic sanctioning of transplantation was the strongest positive influence for donation (Al-Faqhi, 1991 cited in Feroz Ali et al, 2013).

4.8 Summary

Overall, findings from research among Muslims in Europe – the majority of which has been conducted in the UK (under an opt-in system) among South Asian Muslims – reflect the division in opinion regarding organ donation in Islam. Many Muslims are uncertain of Islam's stance or believe it to oppose donation, regardless of the consent system. There appeared to be little awareness that many Islamic scholars support organ donation, or of the numerous fatwas passed reflecting this. However, the desire expressed for more information about organ donation in some of the research suggests that there is scope to improve engagement.

Although only a small amount of pertinent research conducted in Muslim countries has been identified, the similarity across the findings suggests that religious and cultural concerns remain barriers to deceased donation, reflected in the low deceased donation rates. This, coupled with low levels of awareness about the transplant process supports what has also been found among Muslims in the UK context. However, these exist alongside the arguably bigger barriers to donation posed by poorly resourced transplant infrastructure and poorly regulated transplant systems (Vathsala, 2004; Shaheen, 2009). Given the complex interplay of the barriers faced, it is possible that presumed consent is unlikely to be adopted easily in predominantly Muslim countries.

Within the context of Wales and the UK, local grassroots initiatives utilising a peer education model and religious leaders may have more success at communicating information regarding Islam and organ donation. This has been recognised by the authors of much of the research conducted in Europe and has also been included in current engagement strategies for BME groups, whereby the NHSBT is seeking to work in partnership with faith leaders (NHSBT, 2013^c). Evidence of a peer education approach adopted by Kidney Research UK in London has shown that the peer-led approach may be a successful strategy; resulting in increased numbers of BME individuals

¹³ Pakistan only introduced its own organ donation legislation in 2007 in an effort to curb organ trading. This survey interviewed 158 students from Ziauddin Medical University.

¹⁴ Survey of 243 health care professionals based in two different hospitals.

¹⁵ Based on a convenience sample of 440 individuals in Karachi, Pakistan.

signing the organ donor register through engagement with community members at large events. It has recently been rolled out as a two year project in Birmingham (See Jain et al, 2013) and currently being piloted in Scotland (Churchill, 2014).

5. Research exploring the role of Hinduism and Sikhism in organ donation

This chapter brings together research investigating the relationships of Hinduism and Sikhism with organ donation and presumed consent. Given the relatively limited evidence base for Hinduism and Sikhism, and the close relation of their core values and beliefs, the evidence concerning these two religions is considered within the same chapter.

5.1 Organ donation in India

Although there is nothing within Hindu or Sikh principles that either accepts or rejects organ donation, there remain significant barriers to donation in India, where Hinduism is the majority religion. Deceased organ donation is relatively new in India, with the Transplantation of Human Organs Act only being initiated in 1994. However, the rate of deceased donation remains low at 0.08 PMP per year (Abraham et al, 2010; Annadurai et al, 2013). This has been attributed to a number of factors including a lack of knowledge about organ donation and brain death, limited public healthcare provision, and high levels of medical mistrust (Veerappan, 2012).

In terms of what is known about religious barriers to deceased organ donation in India, research by Annadurai et al, (2013) found that religious permissibility was not a major factor in determining willingness to donate, although another study conducted by Sucharitha et al (2013) indicated that religion may act as some sort of barrier. Both studies identified a lack of knowledge about organ donation, with few respondents having a clear understanding of what organ donation is, or its legality.

This is supported by research conducted by Mithra et al, (2013), which found poor knowledge and understanding of brain death, which organs could be donated, or being aware of the organ donor register. However, it did find that willingness to donate was significantly higher among Hindus than it was for Muslims. Nevertheless, an audit of organs donated from brain dead patients in one major Indian hospital showed that organs were only donated by family members in 19 per cent of cases (Shroff et al, 2003).

Among respondents who were unwilling to donate organs after death in Mithra et al's (2013) research, the main reasons were bodily integrity, religious reasons, and family refusal. These three reasons were also cited in Sucharitha et al's (2013) research with family refusal being the most common (see also Little Flower and Balamurugan, 2013). Cultural and religious beliefs, such as beliefs about bodily integrity and the need to be whole for reincarnation, may still exert an indirect influence on individuals through family pressure to respect and uphold rituals surrounding death. The finding that fewer people were willing to sign the donor card than those who claimed they would be willing to donate, suggests that this may be something that warrant further exploration (Mithra et al, 2013).

5.2 Hinduism, Sikhism and religious permissibility

In the UK, cultural issues concerning bodily integrity are found to be a major barrier to willingness to donate among South Asians¹⁶. However, the influence of faith is difficult to unpack as barriers are multiple and common across the South Asian population.

Karim et al (2013) found that while nine out of ten Hindus agree with organ donation, fewer than half believe it to be permissible in Hinduism. The majority of concerns about organ donation related to bodily integrity, with the belief that if they were to donate an organ after death, reincarnation may be compromised (Randhawa, 1998; Darr and Randhawa, 1999; Gauher et al, 2013).

Questions regarding religious permissibility may not be as much of an issue among Sikhs, as they are found to be more likely to know that organ donation is compatible with their faith than Hindus and Muslims (Exley et al, 1996; Randhawa, 1998; Gauher et al, 2013; Karim et al, 2013). In Karim et al's (2013) study, the majority of Sikhs agreed with organ donation and believed it to be compatible with their faith. However, as has been found among Hindus, concerns about bodily integrity and the potential negative implications organ donation may have for reincarnation act as barriers to willingness to donate (Randhawa, 1998; Gauher et al, 2013). This also reflects earlier qualitative research among Sikhs in the UK by Exley et al (1996)¹⁷. This research also found a general lack of awareness regarding the donation process or of its relevance for the South Asian community, with most participants claiming to have never given organ donation any thought. Research also suggests that parental pressure, although important, may be less of a barrier among Sikhs. This was subjectively ranked as less of a barrier to donation among Sikhs than it was for Hindus and Muslims in Karim et al's (2013) research.

Evidence also points to a stronger influence of the family on organ donation decisions for Hindus compared with Muslims (Gauher et al, 2013; Karim et al, 2013). This may limit willingness to donate among Hindus regardless of positive personal attitudes to organ donation and awareness of religious permissibility. This is because the attitudes of the older generation were believed to more likely reflect non-Western views, and tend to be negative due to organ donation being viewed as a taboo topic. While younger generations tended to dismiss these negative views, overall deference to the decision of elders may lead to fewer Hindus registering as organ donors (Gauher et al, 2013).

In line with other research among the South Asian population, a lack of awareness about organ donation and the need for organs among this group, and medical mistrust, also act as barriers to donate among Hindus

¹⁶ Although it must also be noted that in line with the demographic of South Asians in the UK, the majority of the respondents were of Bangladeshi and Pakistani origin and Muslim. Furthermore, little in the way also exists in terms of large scale survey data into this group in both India and the UK, making it difficult to generalise the results.

¹⁷ Interviews conducted with 22 Sikhs in Coventry, identified using purposive sampling.

(Randhawa, 1998; Darr and Randhawa, 1999; Gauher et al, 2013; Karim et al, 2013).

Therefore religious permissibility possibly acts as less of a barrier to donation among Sikhs than Hindu and Muslim members of the South Asian population. However, other barriers to donation, reflecting those of the South Asian population in general, still exist.

5.3 Attitudes to presumed consent systems

Little is known about consent preferences among Hindu and Sikh populations. However, de Looze and Shroff (2012) urge caution about the potential acceptability in India of a presumed consent system given the barriers surrounding donation in India, and the fact that opt-in legislation has only been passed relatively recently.

In terms of what is known in the UK, Randhawa et al's (2010^a) research among faith leaders suggests that it may not be the preferred consent choice. Of the four Hindu representatives interviewed, only one stated a preference for an opt-out system, with the other three representatives preferring an opt-in system. This preference was due to beliefs that an opt-out system undermines individual autonomy. Both Sikh representatives were supportive of organ donation and favoured the current opt-in system, raising similar concerns to opt-out as the other faith representatives. The main issue for Sikh representatives concerned assuming consent for those who may have wished to opt out but failed to do so. Hindu and Sikh faith leaders felt that there should be more local level engagement and grassroots initiatives to raise awareness of the importance of organ donation.

5.4 Summary

Overall, the barriers to organ donation among Hindus are multiple, reflecting the wider barriers experienced by South Asians. The Hindu faith perhaps represents less of a barrier to donation than cultural factors concerning family approval and death rituals. It is possible that these barriers could be removed through better education on organ donation and its religious permissibility, especially given the lack of knowledge and awareness that has been found.

Religious concerns appear to have less relevance for Sikhs than they do for Muslims and Hindus, although conclusions must be taken with caution due to the small sample sizes in much of the research. Barriers to donation among Sikhs reflect those found among the South Asian population in general. Research also suggests that despite questions of religious permissibility not being a concern, the utilisation of faith leaders may be an effective approach to engage Sikhs with the importance of organ donation (Randhawa et al, 2010^a). Indeed, this was mirrored by participants in Exley et al's (1996) research who felt that more Sikhs may be willing to join the organ donation register if faith leaders were used to communicate on the matter. This lends further support to the idea that grassroots campaigns may be more effective at engaging the South Asian population (Darr and Randhawa, 1999), and is

reflected in the current strategies to engage BME groups (see NBTA, 2013; NHSBT, 2013).

6. Research exploring the role of Buddhism in organ donation

6.1 Attitudes to brain death

There is nothing within Buddhist teaching that explicitly accepts or rejects organ donation. On the whole Buddhist teachers have tended to support organ donation, seeing it as a compassionate act in keeping with the principles of Buddhism. However, within some Buddhist traditions, lack of acceptance of brain death presents a major barrier to deceased donation (Keown, 2010). Indeed, deceased donation remains low across much of Asia where Buddhism is predominantly practiced. For example, the deceased donation rates in Japan and Hong Kong are 0.9 PMP and 7.2 PMP respectively (IRODaT, 2013).

In Japan, strong resistance to the concept of brain death exists due to its association with organ transplantation. This has been attributed to the influence of Confucian spiritual values which emphasises the need for individuals to return their bodies in the same condition they received them out of respect for their ancestors (LaFleur, 2001 cited in Keown, 2005) and has prevented the potential utilisation of deceased donors. The Buddhist emphasis on an uninterrupted dying process being important for a peaceful passage into the next life also forms part of this resistance (Hughes and Keown, 1995). However, no research was found on attitudes and behaviour towards organ donation in the predominantly Buddhist countries of South-East Asia, and scant research found in countries with large Buddhist populations such as China and Japan.

Survey data from China suggests that it may be traditional Chinese Confucian beliefs rather than Buddhist beliefs which act as a barrier to becoming a donor. For example, research by Wang et al (2012)¹⁸, found that the majority of respondents knew and approved of organ donation (95 and 90 per cent respectively), and nearly three quarters also stated that they would be willing to donate their organs after death. Of those unwilling to donate, the main barriers were beliefs about bodily integrity and fear of organs being sold on the black market. However, the illegality of taking organs from brain dead individuals in China plays a significant barrier to deceased donation and the authors speculate that the introduction of such legislation is unlikely given strong cultural resistance.

Research conducted in Japan by Bagheri et al (2003)¹⁹ where legislation for organ transplantation (including recognition of the brain death criteria) was passed in 1997, supports this. Despite the majority of respondents agreeing with donation from deceased, living donors and brain dead donors, attitudes to brain death were mixed. For example, six out of ten respondents regarded brain death as real, yet the same proportion also believed brain death to be treatable, evidencing confusion on the issue. The majority also regarded

¹⁸ Survey conducted in an outpatient hall and four colleges among 2,930 randomly selected individuals.

¹⁹ Survey of 383 students.

removal of organs from a brain dead patient as mutilation. Those who accepted brain death were significantly more likely to be willing to donate, illustrating its influence. The role of the family may also act to compound this further due to the power of veto they currently have in Japanese organ transplantation law (Bagheri et al, 2003).

6.2 Cultural and religious perspectives

The studies discussed above suggest that cultural resistance to accepting brain death may act as a significant barrier to deceased donation in Japan and China. However, neither looked into the influence of faith, making it difficult to tell the degree to which attitudes to organ donation and brain death are cultural or religious. Research conducted among Chinese Buddhists elsewhere suggest that it is more likely cultural than religious beliefs which act as barriers to donation, with the need for bodily integrity being the most commonly cited. For example, qualitative research by Wong (2010) in Malaysia found that Chinese Buddhists tend to believe that Buddhism supports organ donation, yet expressed concerns about the donation process due to beliefs in the need for an intact body for entry into the next life. Family disapproval was also a barrier. This indicates that there may be strong cultural barriers to deceased donation among Chinese Buddhists.

The same concerns about bodily integrity have been raised in research on attitudes to organ donation in the West among individuals of Chinese ethnicity. For example, Lam and McCullough's (2000)²⁰ research among Chinese Americans found that despite the majority of participants being Christian, most tended to also agree with non-Christian beliefs about organ donation (for example, in the Confucian belief in the need for bodily integrity), illustrating the complexity of belief systems which may influence attitudes to organ donation.

Overall, Confucian beliefs about bodily integrity were associated with a willingness to donate, with less than half being willing to donate their organs to strangers after death for this reason. Willingness to donate increased if the recipient was either a distant relative or an immediate family member, reflecting the emphasis on the family in Confucian values (Lam and McCullough, 2000). Similar findings were also apparent in research conducted by Alden and Cheug (2000) among American Asians and Molzhan et al (2005) among Canadian Chinese, with participants in Molzhan et al's research attributing their beliefs about organ donation to old Chinese ways and taboos about discussing death (Alden and Cheung, 2000; Molzhan et al, 2005).

²⁰ A survey of 150 attendees of a non-denominational Chinese American Church, which attracts both Christian and non-Christian Chinese Americans.

6.3 Attitudes to presumed consent systems

Little is known about consent preferences among the Buddhist population. In terms of what is known in the UK, the research conducted by Randhawa et al (2010^b) among faith leaders suggests that it may not be the preferred consent choice. The two representatives from the Buddhist society and the Network of Buddhist Organisations were supportive of organ donation and the current opt-in system but had reservations about an opt-out system due to concerns about it undermining individual autonomy. Although it was recognised that individuals would still have a choice under an opt-out system, it was felt that individuals may perceive their relationship with the state to be imbalanced (Randhawa et al, 2010^b). As found with the research among all faith representatives mentioned so far, these concerns are not strictly religious in nature but are grounded in ethical concerns regarding the individual.

6.4 Summary

Overall, it is perhaps a mixture of beliefs within Asian culture rather than purely Buddhist beliefs which influence attitudes towards organ donation. However, given that the research conducted in China and Japan did not explore the influence of Buddhism, and the lack of research in Buddhist countries generally, conclusions should be taken with caution. Lack of acceptance of brain death appears to be a particular issue in China and Japan, and is a common barrier to deceased donation across Asia (Shroff, 2010). Given how the different religious belief systems in China have become intertwined over the centuries due to the similarities in value systems, both cultural and religious factors are likely to be at play regardless of whether individuals are practicing Buddhists (Lam and McCullough, 2000).

As the research predominantly considered individuals of Chinese ethnicity (the majority of whom were not practicing Buddhists), it would be interesting to investigate whether these beliefs are present in practicing Buddhists of different ethnicities, such as in the UK, where Buddhism is ethnically diverse. Findings from Alden and Cheung (2000) suggest that attitudes to deceased donation may be similar across the different ethnicities of Asia due to shared religious histories influencing cultural beliefs about death and the dying process. Interestingly, what the research conducted in Western countries does show is how Chinese cultural beliefs and values still hold despite donation being more commonly practiced and accepted.

7. Research exploring the role of Judaism in organ donation

7.1 Organ donation in Israel

Although Judaism supports organ donation in theory, in practice decisions can be difficult, with some Orthodox Jews opposing organ donation due to the definition of death in Jewish law. Similarly to Islam, the Jewish principles of saving a life (pikauch nefesh) and the honour and respect that is due to the dead (kavod hamed), come into conflict with one another when it comes to the matter of organ donation (NHSBT, 2012^f). Reflective of this tension is the fact that Israel, which has a predominantly Jewish population, has one of the lowest deceased donation rates among developed countries, with the recent figure showing it to be 7.3 PMP (IRODaT, 2013).

Low donation rates have been attributed to the belief that Judaism prohibits deceased organ donation, due to how death is defined under Halachic law (Pikar, 2003 cited in Scott and Jacobsen, 2007). Disagreements regarding the definition of brain death between rabbinic authorities and physicians were only settled in 2008, with both bodies coming to an agreement on the processes under which brain death is defined, resulting in the passing of a new Organ Transplant Law in Israel. However, resistance to the acceptance of brain death remains, with not all rabbinic authorities accepting it (Jokowitz, 2008; Bresnahan and Mahler, 2010; Sacks, 2011).

Legislative efforts to improve donation rates have also included the introduction of a prioritisation system, where individuals who sign an organ donor card are prioritised on the transplantation waiting list should they ever need a transplant. However the role of the family remains strong in Israeli legislation, with the family being able to overrule wishes of the deceased, although this tends to be rare. For this reason the Israeli government encourages individuals to sign an organ donor card to increase donor rates (ADI, 2008). So far, figures indicate this legislation may have resulted in a modest increase in the percentage of registered donors among the Israeli population (Lavee et al, 2013).

7.2 Research identifying religious concerns

Research suggests that religious concerns may play a major barrier to consent among Israeli Jews. For example, available hospital data on family refusal or consent for organ donation shows that of 262 potential donor families approached, just under half (128) consented for donation to go ahead. The data suggest that religious concern is the most common reason for refusal with nearly 60 per cent of all respondents citing religion as their reason. Data breaking this down by religious group is not available but given the majority of the potential donor families approached were Jewish (72 per cent), it is likely that religious concerns within Judaism may play a major barrier to deceased donation in Israel (Ashkenazi et al, 2004)²¹.

²¹ Data gathered from 22 general hospitals to identify reasons for family consent or refusal.

Further illustrating the influence of religion, research by Feld et al (1998) among Jews living in Canada²² found that the belief that organ donation was prohibited under Jewish law acted as a significant barrier to individuals' willingness to sign an organ donor card. In addition, around half of those surveyed said they would seek a rabbi's advice before signing an organ donor card (Feld et al, 1998).

Research among medical professionals also suggests that issues around brain death may still act as a significant barrier to deceased donation (Cohen et al, 2008; Roels et al, 2010). Cohen et al (2008)²³ found that although eight out of ten critical care staff accepted brain death as a valid determination of death, many were uncomfortable performing key donation-related tasks (Table 7.1).

Table 7.1: Attitudes of critical care staff in Israel

| Donation-related task | % who feel comfortable carrying out task |
|--|---|
| Informing transplant co-ordinator of potential donor | 78 |
| Providing support for a grieving family | 72 |
| Explaining brain death to family | 43 |
| Raising the subject of organ donation | 34 |
| Approaching the family about donation | 28 |

Source: Cohen et al (2008)

Although those who were accepting of brain death were significantly more likely to be comfortable with donation-related tasks, many were still uncomfortable with tasks such as approaching the family, explaining brain death, and raising the subject of organ donation, contributing to potential loss of donor opportunities. Furthermore a significant number of staff also stated that they were not involved in these tasks, with the reasons for this not known. The authors speculate that this may be due to underlying resistance, or to health care professionals being unfamiliar with the donation process. Indeed, international research by Roels et al (2010)²⁴ found that only 64 per cent of critical care unit staff in Israel were willing to donate their organs after death (the lowest percentage out of all countries included in their research, excluding Japan), despite nine out of ten being supportive of organ donation.

Therefore, despite positive attitudes to organ donation and acceptance of brain death among health care professionals, resistance to brain death embedded in Israeli culture as a result of religious concerns may explain lack of confidence in donation-related tasks, creating barriers to deceased

²² Survey of attitudes to organ donation, and understanding of organ donation under Jewish law, among 232 Jews from Orthodox (36), Reform (29), Conservative (155), and other (12) denominations.

²³ Healthcare Attitudes Survey (HAS) – a self-report attitudes study among critical care staff in all hospitals in Israel (N=2,366) to assess attitudes to brain death and level of comfort with performing donor related tasks.

²⁴ An international survey of 19,537 critical care staff across 11 countries (Israel: N=1,946).

donation. Given the historical controversy surrounding brain death under Halachic law and Jewish beliefs about how a dead body should be treated, it may be that despite acceptance of organ donation and brain death by rabbinic authorities, perceived religious prohibition remains a significant barrier to donation among Jews (Feld et al, 1998; Ashkenazi et al, 2004).

7.3 Attitudes to presumed consent systems

Little is known about consent preferences among the Jewish population. Given high family refusal rates due to the religious concerns noted above, it is perhaps unlikely to be popular. Indeed, recent ministerial debates considering the potential introduction of an opt-out system in Israel resulted in the proposal being rejected due to the ethical concerns presuming consent may raise (Fiske, 2014).

In the UK, Randhawa et al (2010^b) found that Jewish representatives feared that such legislation may result in a backlash against donation as a result of individuals feeling that their choice is being removed. Concerns were also raised by Jewish representatives in south Wales in response to consultation on the Human Transplantation (Wales) Bill, with fears that the legislation may undermine the role of the family, as some Jews would traditionally consult a Rabbinic authority before coming to a decision about whether to donate the organs of a deceased family member (Soffa, 2012).

7.4 Summary

Overall, the few research studies that have been identified suggest that perceived religious prohibition acts as a major barrier to donation among Jews (Feld, 1998; Ashkenazi et al, 2004; Scott and Jacobson, 2007). Engagement with faith leaders and the Jewish community may therefore help to raise awareness about organ donation and the acceptability of brain death under Halachic law. This may be particularly important among denominations where the greatest resistance to brain death remains.

8. Concluding remarks

This review set out to explore the relationship between religious beliefs and organ donation, with a particular focus on presumed consent. It is apparent that attitudes to organ donation are influenced by a number of factors, of which religion is just one, making it difficult to unpick the role of faith within this. Some of the key findings of this review are:

- A range of studies provide evidence that barriers to organ donation that are perceived as religious may actually be indicative of cultural norms that transcend religion (for example, the belief in bodily integrity).
- The interplay of faith, religion, and wider cultural norms on their relationship with views on organ donation are complex and difficult to unpick.
- Strength or conservativeness of religious belief, rather than the teachings of the faith, may influence attitudes towards organ donation.
- There is evidence that the subjective norms (the values of those closest to you) can act as an indirect barrier to organ donation. For example, where individuals have a positive attitude to donation but perceive the view of their families to be negative, possibly as a result of religious beliefs.

The review has also helped identify messages and methods for engaging with different faith groups, for example:

- Providing information about the organ donation process to allay misconceptions with regard to bodily integrity or mutilation.
- Engagement with faith leaders and grassroots networks among faith and BME groups where their influence is important, and where there are high levels of medical mistrust. For example, the role of faith leaders could be utilised in Muslim communities to raise awareness regarding Islam's stance on organ donation.
- Engagement with faith leaders is also important where they too have little knowledge or understanding of the organ donation process.
- A peer-led approach may be effective in communities where family relations are a particularly important source for gaining culturally sensitive health information.

Finally, this review has identified evidence gaps where further research could add value to communication and engagement strategies. For example:

- The degree to which religious leaders' views about organ donation and presumed consent influences or reflects that of lay followers. The

survey of Christians living in Wales included in this report provides a small insight into this but more research may be useful.

- More research with Muslims of different ethnicities would be helpful in order to disentangle cultural and religious beliefs.
- Of the major religions, understanding of the attitudes to presumed consent among Buddhists, Hindus and Sikhs is particularly lacking.
- More research exploring concerns about bodily integrity in order to better understand the nature and roots of these beliefs in culture or religion.

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Annex A: Survey questions

The National Assembly for Wales has passed a law to change the organ donation procedure to a 'soft opt out' system. From December 2015 people will be given the opportunity to formally 'opt out' of organ donation by placing their name on a register. If they choose not to do so, having had the opportunity, then this will be treated as a decision to be a donor, and one which families will be sensitively encouraged to accept. The law will allow family members to object to donation on the basis that they know the deceased person would not have wished to consent. The opportunity to 'opt in' and register a decision to be a donor will continue.

1. Were you aware of this legislative change before today?

Yes
No
Don't know

2. Where did you hear about changes to the legislation?

Radio
Television
Website/online
Poster
Newspaper/Magazine
Friends/Family
Work/Educational Institution
Church
Other, please specify

3. Which of these statements about changes to the organ donation system in Wales best reflects your view?

I am in favour of the changes
I am against the changes
I need more information to decide
I don't know

4. To what extent do you agree or disagree with following statements?

- **The soft opt-out system will result in more lives being saved**
- **The soft-opt out system maintains freedom of choice because anyone can opt-out if they want to**
- **Organ donation is a gift that the soft-opt out system will take away**
- **The soft-opt out system gives the government too much control**

Strongly Agree
Agree
Neutral
Disagree
Strongly Disagree

8. What do you think you will do when the new soft-opt out system of organ donation is introduced?

I will opt-out

I will opt-in

I've already registered a wish to be a donor and would take no further action

I've not registered a wish to be a donor and don't think I would opt out of being one

I don't know

9. Would you be willing to accept an organ if needed?

Yes, definitely

Yes, probably

No, probably not

No, definitely not

Not sure

10. Would you be willing to donate an organ?

Yes, definitely

Yes, probably

No, probably not

No, definitely not

Not sure

11. Would you be willing to agree to the donation of a deceased loved one's organs if they had not opted out?

Yes, definitely

Yes, probably

No, probably not

No, definitely not

Not sure

12. Are you currently on the organ donor register?

Yes

No

Don't know

11. How many religious ceremonies have you attended in the last four weeks?

None

1-2

3-4

More than 4

12. Do you think your local priest/pastor/vicar favours organ donation in general?

Yes, definitely
Yes, probably
No, probably not
No, definitely not
Not sure

13. Do you think your local priest/pastor/vicar supports the soft-opt out system?

Yes, definitely
Yes, probably
No, probably not
No, definitely not
Not sure

14. Do you think your religious denomination favours organ donation in general?

Yes, definitely
Yes, probably
No, probably not
No, definitely not
Not sure

15. Do you think your religious denomination supports the soft-opt out system?

Yes, definitely
Yes, probably
No, probably not
No, definitely not
Not sure

16. Do you have any other comments about your faith's views on organ donation?

17. Do you have any other comments about your faith's views on soft-opt out?

Annex B: Survey sample demographics

Total percentages may be over 100 due to rounding.

Table B.1: Gender

| Gender | N | % |
|--------|----|----|
| Female | 67 | 58 |
| Male | 49 | 42 |

Table B.2: Age

| Age | N | % |
|----------|----|----|
| Under 35 | 10 | 9 |
| 35-54 | 24 | 21 |
| 55+ | 81 | 70 |

Table B.3: Denomination

| Denomination | N | % |
|-------------------------|----|----|
| Anglican | 57 | 49 |
| Presbyterian / reformed | 23 | 20 |
| Protestant | 16 | 14 |
| Methodist | 13 | 11 |
| Baptist | 4 | 3 |
| Pentecostal | 1 | 1 |
| Other | 2 | 2 |

Table B.4: Region of Wales where resident ^a

| Region | N | % |
|----------------------------|----|----|
| North Wales | 46 | 40 |
| Swansea Bay | 24 | 21 |
| Mid & West Wales | 21 | 18 |
| Cardiff & South East Wales | 19 | 16 |
| Valleys | 5 | 4 |

(a) Grouped from a list of the 22 unitary authorities in Wales.